S. HRG. 107–92

SPECIAL OLYMPICS REPORT

HEARING

BEFORE A

SUBCOMMITTEE OF THE

COMMITTEE ON APPROPRIATIONS

UNITED STATES SENATE

ONE HUNDRED SEVENTH CONGRESS

FIRST SESSION

SPECIAL HEARING

MARCH 5, 2001—ANCHORAGE, ALASKA

Printed for the use of the Committee on Appropriations

Available via the World Wide Web: http://www.access.gpo.gov/congress/senate

U.S. GOVERNMENT PRINTING OFFICE

71–288 PS WASHINGTON : 2001

For sale by the U.S. Government Printing Office
Superintendent of Documents, Congressional Sales Office, Washington, DC 20402

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SPECIAL OLYMPICS REPORT

MONDAY, MARCH 5, 2001

U.S. SENATE,
SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, AND EDUCATION, AND RELATED AGENCIES,
COMMITTEE ON APPROPRIATIONS,
Anchorage, AK.

The subcommittee met at 10:05 a.m., in Sheraton Anchorage Hotel, Anchorage, AK, Hon. Ted Stevens presiding.

Present: Senator Stevens.

OPENING STATEMENT OF SENATOR TED STEVENS

Senator STEVENS. Thank you all very much. I noticed the bulletin board as we came in said the downhill is canceled for bad weather. Welcome to all the skiers.

Today our Committee on Appropriations is convening this special field hearing of the Subcommittee on Labor and Human Services and Education to receive from the Special Olympics the report on the health status and needs of persons with mental retardation. I have here with me Bettilou Taylor, who is the chief clerk of that subcommittee. The chairman is Senator Arlen Specter, and I am conducting the hearing today for him.

I understand that many of you have important information to present to us today. Before you do, I want to express my appreciation to the Special Olympics for holding the 2001 Special Olympics World Winter Games here in Anchorage. That was a marvelous beginning last night, and I want to thank my son Ben, the president and CEO of the 2001 Special Olympics, the World Winter Games Organizing Committee, Patty McGuire, who is the president and the board of the Special Olympics World Winter Games here in Anchorage. It has been a long trail to this time, and everything is coming together in a marvelous way.

We are here today to receive the report and hear from some witnesses who will help us understand the special health needs of persons with mental retardation. It is worth noting the remarkable history behind this organization. The Special Olympics began in 1968, when Eunice Kennedy Shriver organized the First International Special Olympics, held at Soldiers Field in Chicago.

You might say that the flame that lights the Special Olympics was sparked by Ms. Shriver at that time, in her deeply held conviction that individuals with mental retardation are far more capable in sports and physical activities than experts were willing to recognize then. We are honored to have with us today Eunice and Sargent Shriver. Thank you very much for being here.

I might say, as some of you know, I was on the other end of that situation. I was raised by my aunt and uncle, who had a daughter with mental retardation, and I saw then how people with those conditions were treated in the days of the thirties and forties. It is a wonderful change that has been brought about today. All of us who have family members, Ms. Shriver, thank you very much for all you have done to bring attention to this condition.

Fueled by her vision, the Special Olympics has grown into an international program of year-round sports training and athletic competition for 1 million children and adults with mental retardation. Special Olympics programs now exist in 160 nations. New programs are continuing to be developed around the world.

The only thing more remarkable than the Special Olympics itself are the people who participate in it. The pride and dedication of these athletes that they show lifts our hearts, and more than that, these athletes are a source of strength for all of us, because they confirm what we all want to believe, that the human spirit can overcome any diversity and that really is what I think Special Olympics is all about.

The report that we are going to receive emphasizes the urgent need to identify scientific knowledge, and develop programs to improve the quality and length of life for persons with mental retardation, most notably, Special Olympic athletes.

In 1999, when the Special Olympics commissioned this report, information on the health conditions of people with mental retardation simply did not exist. The report clearly identifies the problems, and makes recommendations to address the health needs of 170 million persons with mental retardation worldwide, and I applaud again the Special Olympics for commissioning this report, but then, I am not surprised that they would have taken on such a task. The Special Olympics has never been afraid to take on great challenges.

We have distinguished witnesses today and we will begin with Timothy Shriver and Cindy Bentley. Let me lay down some guidelines, if I may, for this testimony. We normally establish a 5-minute time limit for witnesses, I would hope if you would help us by confining your comments as much as possible. There is a light system here that we sort of follow. It depends on the circumstances, but it will go on when your limit has been reached, and because of the time, and what we have scheduled immediately after this hearing, we will have to end the precedings precisely at 12 noon. I hope that you will keep in mind the people that will be testifying after you.

INTRODUCTION OF DR. SHRIVER AND MS. BENTLEY

Let me introduce Dr. Timothy Shriver, who you all heard last evening. He is president and chief executive officer of the Special Olympics, Inc. He served as president of the 1995 Special Olympics World Games Organizing Committee. Prior to joining the Special Olympics, Dr. Shriver launched and was supervisor of the New Haven, Connecticut, Public Schools Social Development Project. Dr. Shriver earned his undergraduate degree at Yale, a master's degree from Catholic University, and holds a doctorate in education from the University of Connecticut.

Cindy Bentley is a Special Olympics athlete from Wisconsin, and member of the Sargent Shriver Global Messengers Class of 2000–2001. Ms. Bentley attended her first Special Olympics International Games in 1968 in Chicago, and has competed in both the 1995 and 1999 World Summer Games. She won medals in basketball, track, speed skating, volley ball, and tennis.

I would like to proceed with your testimony now. I understand we do have a scheduled list of witnesses. If anyone really feels that they should be heard, please contact Bettilou or a member of our staff.

Thank you very much. Tim.

Dr. SHRIVER. I think Cindy is going to start.

Senator STEVENS. Okay, Cindy.

STATEMENT OF CINDY BENTLEY, SPECIAL OLYMPICS ATHLETE, WISCONSIN, USA

ACCOMPANIED BY THE SARGENT SHRIVER GLOBAL MESSENGERS CLASS OF 2000–2001:

GORAN BABIC, BOSNIA AND HERZEGOVINA

TROY FORD-KING, ONTARIO, CANADA

KEALOHA LAEMOA, HAWAII, USA

HERY MORETTI, RHODE ISLAND, USA

MOHAMMAD NASSAR, JORDAN

MIGUEL QUIROZ, VENEZUELA

JIA SIRUI, CHINA

VICTOR STEWART, TEXAS, USA

THEO TEBELE, BOTSWANA

CONSTANTINOS TRIANTAFYLOU, HELLAS, GREECE

KATY WILSON, GEORGIA, USA

Ms. BENTLEY. Good morning.

Senator STEVENS. Just pull the mike closer to you, Cindy.

Ms. BENTLEY. Good morning. My name is Cindy Bentley. Mr. Chairman, I am grateful that you are holding these hearings about the health care needs for persons with mental retardation. I am a Special Olympics athlete from Wisconsin. I have won medals in basketball, track, speed skating, volley ball, and tennis. I am Governor Thomson's appointee to the Wisconsin Council on Development Disabilities. Now that Governor Thompson is the Secretary of Health and Human Services, I hope he will still listen to me, especially on health care.

Mr. Chairman, I am especially proud to be a Special Olympic Global Messenger. Every 2 years a new class of 12 Special Olympics Global Messengers is selected from hundreds of nominees submitted by Special Olympics programs from around the world. These 12 Global Messengers represent the international organization by attending major events around the world, and by serving as spokespersons for Special Olympics, educating people everywhere about the mission of Special Olympics.

You may remember me as one of the Global Messengers who attended the Torch Lighting ceremony in Greece. I was so happy that you honored the 2001 World Games by participating in that ceremony at the birthplace of the Olympics.

PREPARED STATEMENT

I am joined here today by all of the current Special Olympics Global Messengers. Together, we are honored to present you and the committee with this report, entitled, "The Health Status and Needs of Individuals with Mental Retardation."

Thanks again for holding this hearing.

[The statement follows:]

PREPARED STATEMENT OF CINDY BENTLEY

Good morning. My name is Cindy Bentley. Mr. Chairman, I am grateful that you are holding this hearing about the health care needs of persons with mental retardation.

I am a Special Olympics athlete from Wisconsin. I have won medals in basketball, track, speed skating, volleyball, and tennis. I am Governor Thompson's appointee to the Wisconsin Council on Developmental Disabilities. Now that Governor Thompson is the Secretary of Health and Human Services, I hope he will still listen to me, especially about health care.

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I am joined here today by the all of the current Special Olympics Global Messengers. Together, we are honored to present you and the Committee with this report, entitled The Health Status and Needs of Individuals with Mental Retardation.

Thanks again for holding this hearing.

WHAT IS SPECIAL OLYMPICS?

Special Olympics is an international program of year-round sports training and athletic competition for more than one million children and adults with mental retardation.

The Special Olympics oath is: Let me win. But if I cannot win, let me be brave in the attempt.

Our leaders are: Eunice Kennedy Shriver, Founder and Honorary Chairman; Sargent Shriver, Chairman of the Board; and Timothy P. Shriver, Ph.D., President and CEO.

Our mission is to provide year-round sports training and athletic competition in a variety of Olympic-type sports for children and adults with mental retardation by giving them continuing opportunities to develop physical fitness, demonstrate courage, experience joy, and participate in a sharing of gifts, skills, and friendship with their families, other Special Olympics athletes and the community.

Our goal is for all persons with mental retardation to have the chance to become useful and productive citizens who are accepted and respected in their communities.

The benefits of participation in Special Olympics for people with mental retardation include improved physical fitness and motor skills, greater self-confidence, a more positive self-image, friendships, and increased family support. Special Olympics athletes carry these benefits with them into their daily lives at home, in the classroom, on the job, and in the community. Families who participate become stronger as they learn a greater appreciation of their athlete's talents. Community volunteers find out what good friends the athletes can be. And everyone learns more about the capabilities of people with mental retardation.

The Spirit of Special Olympics—skill, courage, sharing, and joy—transcends boundaries of geography, nationality, political philosophy, gender, age, race, or religion.

Special Olympics began in 1968 when Eunice Kennedy Shriver organized the First International Special Olympics Games at Soldier Field, Chicago, Illinois, USA. The concept was born in the early 1960s when Mrs. Shriver started a day camp for people with mental retardation. She saw that individuals with mental retardation were far more capable in sports and physical activities than many experts thought.

Since 1968, millions of children and adults with mental retardation have participated in Special Olympics.

Around the world there are accredited Special Olympics Programs in more than 160 countries. Special Olympics Programs are continually being developed around the world.

In the United States Special Olympics Programs are established in all 50 states, the District of Columbia, Guam, the Virgin Islands, and American Samoa. About 25,000 communities in the United States have Special Olympics Programs.

To be eligible to participate in Special Olympics, an athlete must be at least eight years old and identified by an agency or professional as having one of the following conditions: mental retardation, cognitive delays as measured by formal assessment, or significant learning or vocational problems due to cognitive delay that require, or have required, specially-designed instruction.

The Special Olympics Unified Sports™ program brings together athletes with and without mental retardation of similar age and ability to train and compete on the same teams. Founded in 1987, Special Olympics Unified Sports fosters the integration of persons with mental retardation into school and community sports programs.

Special Olympics provides year-round training and competition in 25 official sports. Special Olympics has developed and tested training programs that are outlined in a Sports Skills Guide for each sport. More than 140,000 qualified coaches train Special Olympics athletes.

By assigning athletes to divisions determined by their ages and ability levels, Special Olympics gives every athlete a reasonable chance to win. Athletes from all divisions may advance to State, National, and World Games.

For athletes with profound disabilities Special Olympics created its Motor Activities Training Program (MATP), developed by physical educators, physical therapists, and recreation therapists. MATP emphasizes training and participation rather than competition. MATP is part of the Special Olympics commitment to offer sports training to all individuals with mental retardation.

Special Olympics competitions are patterned after the Olympic Games. More than 20,000 Games, meets, and tournaments in both summer and winter sports are held worldwide each year. World Games for selected representatives of all Programs are held every two years, alternating between summer and winter.

More than 100,000 volunteers organize and run local Special Olympics programs, serving as coaches, Games officials, drivers, and in many other capacities. Anyone can learn how to participate through the many training programs Special Olympics offers for coaches, officials, and volunteers.

Headquartered in Washington, D.C., Special Olympics guides local, area, state, and national programs around the world. A volunteer board of directors determines international policies and is comprised of business and sport leaders, professional athletes, educators, and experts in mental retardation from around the world.

Giving cooperation and support to Special Olympics are the national governing bodies and/or international sports federations of each sport played in Special Olympics. Major sports organizations and a host of world leaders also support Special Olympics and its goals.

Special Olympics is the only organization authorized by the International Olympic Committee to use "Olympics" worldwide.

For more information about your Special Olympics Program, call 202–628–3630, or visit the Special Olympics website at www.specialolympics.org or AOL keyword: Special Olympics.

Senator STEVENS. Thank you very much, Cindy, and we will take that back to the committee, and it will be printed in our hearing today.

Ms. BENTLEY. Thank you so much, Mr. Chairman.

STATEMENT OF TIMOTHY SHRIVER, Ph.D., PRESIDENT AND CEO, SPECIAL OLYMPICS, INC.

Dr. SHRIVER. Mr. Chairman, Cindy Bentley, Global Messengers, Surgeon General Satcher, members of the Board of Special Olympics, distinguished guests and athletes, Mr. Chairman, let me begin by repeating what Cindy Bentley has just said, which is, we are enormously grateful to you for convening this hearing, for your leadership of these Games, for coming all the way to Athens with

your colleagues from the U.S. Senate to celebrate the lighting of the Flame of Hope.

It is our understanding that this is the first hearing ever convened by a committee of the U.S. Senate exclusively devoted to health issues confronting people with mental disability, and never before in the history of the Republic has a Senate hearing been convened under any circumstances with the exclusive mission of focusing on the needs of this population, a population that is, as we all know, so deserving of an opportunity. This would not have happened, of course, without your leadership, so on this historic occasion, from all of us at Special Olympics, let me again thank you.

The report you have just received, Mr. Chairman, has a long history and many stories associated with it. For me personally, it began at the 1995 Special Olympics World Games. At those Games, I was a part of the staff and volunteers who helped to create a global celebration, just as we are holding here this week. At those Games, we created this first health clinic, eye clinic, oral health clinic, and it was located in the middle of our Olympic Village. I visited the clinics in the early days to talk to the doctors and others. Everybody was having a good time.

When the week ended, we received the data that had been collected as several thousand athletes from those world Games had been screened by medical volunteers, led by Dr. Steve Perlman and Dr. Paul Berman, and what we found was stunning. The data is contained in this report, Mr. Chairman, but I would like to highlight a few findings: almost 30 percent of the athletes screened in those clinics had visual problems or could not see, despite having been treated previoulsy by a doctor. Almost 20 percent were in severe pain.

These are athletes that had been screened by doctors, had been prepared to come to the Games, yet notwithstanding that they were walking around with acute pain so severe that it was interfering with their daily lives. Almost 15 percent of the athletes screened on this occasion had to be referred immediately to the emergency room for care of serious health conditions either related to their oral health care or to their eyes.

What we found as we started to analyze this data, Mr. Chairman, were at least three critical problems. One, the health care professionals that had been trained by medical institutions had chronic gaps in their training, with respect to treating people with mental retardation. We saw severe training issues in the way in which doctors and other health care professionals were being educated.

We saw medical coverage issues. Many of these athletes had medical insurance of one form or another, but it was not covering their dental care or other specialized medical conditions. So many of our athletes, even in wealthy communities, did not have access to anywhere near resembling adequate care.

But perhaps more serious than either of those two problems was the fact that we uncovered what can only be described as discrimination. We found, in summary, that the health care system in the United States and to a large extent, as well as we could understand it, the health care systems around the world, were practicing active discrimination against people with mental disabilities for no

other reason than because they had a disability that made the health care professional uncomfortable.

This was brought home to me as I tried to struggle with this issue not as a doctor, but as a volunteer in Special Olympics, and then as a staff member, by Dr. Paul Berman. He took me aside and said: "you know, Tim, it is like this: Many of these athletes do see a doctor, but they get what we call a quick and dirty.

"That means, after they are brought in, we take the allotted time, we fit them with a pair of glasses or provide some other medical solution. We do not really care because they will not drive a car, they will not operate heavy machinery, they do not fill out legal challenges, and they do not complain, so the doctors are content to give them a quick and dirty. I am not proud of my profession, Tim, but that is the way it is."

That trajectory of information, Mr. Chairman, led us to create this report that we presented to you today. Special Olympics, as you know, has spent 30 years promoting the health condition of people with mental retardation in positive ways through sports training and competition. But I have come to the conclusion that we cannot win the battle for improved health care for people with mental retardation if doctors and the medical profession are the enemy. We cannot provide sports training, we cannot provide competitive opportunities, we cannot promote social and political acceptance if the medical profession is fighting against us, and I am sorry to say, Mr. Chairman, that this report indicates that it is.

What is next? Very simply, we could commit to serving over 100,000 athletes in our health care clinics annually. We could improve the health status of people with mental retardation by increasing our knowledge about their health conditions. Surgeon General Satcher is here today, and we are going to ask him formally to help us with data-collection. If there is one conclusion of this report, it is that the health data does not exist for people with mental retardation because no one has taken the time to gather it, because no one has cared.

We need data. We need to change the reimbursement laws in this country so that people in this country, in the wealthiest country in the world, can at least have access to adequate care. We need to create, or be creative about new ways to improve health care for people with mental retardation. IEPs have been required for people with mental disability in this country in the education system. Why not include a health status component to the IEP so that school-aged children have at least some access to quality health care?

Mr. Chairman, I know my time is limited. We are here on behalf of a population that has no high-paid lobbyists in Washington, that has no well-heeled perks to offer to the Members of Congress or the U.S. Senate, or to other senior policy leaders. We are here on behalf of the humblest people on the planet, and probably the population with the least amount of political influence of any, and yet I hope that we will all commit here today to improve their access to quality health care.

PREPARED STATEMENT

As we come together in celebration at these World Games, we see athletes like Laura Zimmerman who is here today with 16 members of her family, to watch her and take family pride in her downhill skiing. Why is that happening? Why is Laura getting such a warm welcome? Why is she excelling at sports? For one simple reason, Laura was given a chance. If there is one message, Mr. Chairman, it is that we need your voice, and we need the voice of your colleagues, to make it possible for people with mental disability to have a reasonable chance at a healthy life.

Thank you, Mr. Chairman.

[The statement follows:]

PREPARED STATEMENT OF TIMOTHY SHRIVER

Mr. Chairman, distinguished guests, Special Olympics athletes and families, let me begin be saying how proud and honored all of us in Special Olympics are to be a part of this historic hearing. To my knowledge, never before has the Appropriations Committee of the United States Senate convened a hearing on issues related to people with mental retardation—in fact, I understand that this is the first hearing held by any Senate Committee completely dedicated to the needs of people with mental retardation. And for all of us in Special Olympics, this moment represents a first as well. Until today, we have never been offered the chance to speak directly to the leadership of the United States Senate about the hopes and needs and abilities of our athletes.

Senator Stevens, thank you. Thank you for your presence here today, for your presence at our Torch Lighting Ceremony in Athens two weeks ago, for your Honorary Chairmanship of these Games and for your willingness to lead on behalf of our athletes.

Mr. Chairman, six years ago, the Special Olympics World Summer Games were held in my home state of Connecticut. I had the honor or working as part of a statewide team of over 40,000 volunteers and staff members to host the event. At those Games, all the traditional elements of Special Olympics were present: the pomp and ceremony, the cultures of the world on display in breathtaking traditional costumes and rituals, festivities and celebrations, inspiring competition, and moments of transformative family joy.

Those Games were also the first time that Special Olympics hosted a Healthy Athletes screening clinic to promote oral and vision health. Led by Drs. Steve Perlman and Paul Berman, teams of volunteer dentists and optometrists traveled from throughout the country to New Haven to provide screening services and basic health instruction to athletes. I toured the Healthy Athletes Center at the beginning of the Games, and saw athletes receiving instruction in oral hygiene. I saw sophisticated instruments measuring vision and talked with volunteers from the medical community who were having a great time.

And then at the end of the week, I heard the results of what the medical professionals had seen and I was disgusted and shocked. Specifically, 85 percent of the athletes screened had refractive errors in their vision; 28 percent suffered from astigmatism, 25 percent had strabismus; 29 percent had general untreated visual problems and 23 percent of Special Olympics screened athletes failed a test for visual acuity, which is simply the ability to see clearly. Further, 27 percent of the athletes screened had not had an eye exam within three years.

On the oral health front, 68.1 percent of the athletes screened exhibited gingivitis and one in three athletes had active untreated dental decay. More than 20 percent reported pain in the oral cavity. Perhaps, most frightening, almost 15 percent of the Special Olympics athletes who chanced into the Healthy Athletes clinic had to be referred to the Emergency Room due to untreated acute pain or disease. In short, World Games athletes who were otherwise thought to be fine had suffered from such high levels of neglect that when exposed to a health professional, they were found to be sick and in some cases VERY sick. I couldn't believe it.

In the days that followed, I learned more as I tried to find out how these athletes could be suffering so. Where were their doctors? Why had they not received attention? Who was negligent? What was going on? And as I struggled to understand health insurance issues, medical training issues, epidemiology issues, pharmaceutical issues and more, I heard an explanation that I will always remember.

Dr. Paul Berman took me aside and explained. "Tim, in most cases doctors don't want to treat these patients. They either don't know how or they don't see the money. But even when they do, it's not real care. It's a 'quick and dirty.' Give a quick look, give them some glasses and send them on their way. They're not driving or operating heavy machinery. They're not reading or doing legal work. What difference does it make whether or not they see clearly? Get them in and get them out. That's the attitude, Tim. I'm not proud of my profession, but that's the way it is." "Quick and Dirty." I'll never forget those words. In the best case scenario, many people with mental retardation get a "quick and dirty."

As I struggled to comprehend this reality, I began to understand that the health care problems I was discovering were far bigger than Special Olympics but nonetheless part of the problem we were facing in promoting sports training and competition around the world. Quite simply, I realized that children and adults with mental retardation simply could not become athletes if they were sick, especially if they were sick because of neglect and indifference!

Over the last few years, Mr. Chairman, Special Olympics has focused new energy on this issue because we believe that health is related integrally to sport. For years, we have known about the great benefits of participation in Special Olympics: increased skills, transformations in self-confidence and self-esteem, new family pride, changes in community attitudes and more. In general, we are convinced that Special Olympics helps athletes become healthier!

But we can't win the struggle for equitable health care if the medical system is fighting against us! We can't win if the standard is "down and dirty." Doctors and health care professionals are enemies we shouldn't have! In the year 2001, no American should be given a "down and dirty," especially if the reason is blatant and unconscionable discrimination. That simply should not be.

The report we offer to you and to your colleagues on the Senate Appropriations Committee, provides galling evidence in literature from around the world that what we have seen in Special Olympics is no aberration. What it says is actually, a painful reminder of what we thought was a part of the past. We thought the days of isolation and discrimination were over. We thought that all the changes in institutions, in schools, in legal protections, and in housing had changed the situation for people with mental retardation across the board. But now we come face to face with the realization that the health care system has not been part of these changes in anything resembling an acceptable way. In short, Mr. Chairman, the health care system in this country is full of negligence, indifference and blatant discrimination. And around the world, from what we can tell, the situation is not much better.

For example, our report states that in Western Europe and the United States, life expectancy is 74 to 76.5 years. Yet, depending on the severity of their condition, people with mental retardation have a life expectancy of only 53.5 to 66.1 years. The report finds that 39 percent of psychiatrists would prefer not to treat patients who have mental retardation. It finds that as few 30 percent of individuals with mental retardation receive care from medical specialists despite the fact that a full 92 percent had medical needs that required specialty care. This report finds studies on the prevalence of mental retardation and other health conditions are scarce; that barriers to care are numerous and that private and public reimbursement policies are not only inadequate, but also discriminatory.

The key question, Mr. Chairman, is what is next? What can be done?

First, Special Olympic must and will expand our Healthy Athletes program. For many athletes, the free screening clinics they attend at Special Olympics events is the only medical attention they will receive in the course of a year. When we started our work in the health field, we had no special plan for action. In 1995, we held six oral health clinics, and just one focusing on visual health.

Today, thanks to funding from a range of corporate sponsors and thanks to a strong partnership with The Lions Club Foundation, the Healthy Athletes program has taken off. This year, we will host 100 clinics; we will screen and advise 26,800 athletes; we will train nearly 5,000 health care professionals. And we will build the foundation to significantly expand all of these numbers in the years ahead.

One might ask if this is a serious effort and whether or not an organization like Special Olympics can really make a difference in the health status of this population. The answer depends on what one means when one says "health."

If health means only the drugs and operating rooms and the emergency rooms, then Special Olympics cannot contribute. But if health means knowledge about how to take care of oneself, access to the skills and values of prevention, relationships with health professionals that can guide decision making in day-to-day life, and referrals to more significant care when and if it is needed, then Mr. Chairman, Special Olympics can and will be on the cutting edge.

Our commitment is clear. We will continue to focus on sports training and competition and it will remain our greatest contribution to enhancing the health of people with mental retardation around the world. But we will also build a strong Healthy Athletes program and we will do everything we can to demand the attention of health professionals and policy makers alike so that they end the pattern of exclusion, indifference and failure.

But of course, we cannot do it alone, Mr. Chairman and today, I am asking for your support. Please understand that I ask not for myself of even for the movement that I represent. I ask on behalf of roughly seven million Americans and their families who still today, have almost no voice in the public debates of our time. Mr. Chairman, people with mental retardation have no well-heeled lobbyists in Washington; they offer no perks to decision-makers in the halls of power; their economic influence is small; their political influence is almost non existent.

But as you know so well, Mr. Chairman, people with mental retardation in this country have no less right to be treated fairly than anyone else!

If we could find the funds, Special Olympics could screen 175,000 U.S. athletes every year for vision and oral health, hearing, dermatology and orthopedics. And even this number is less than half of the number of athletes who compete at Special Olympics events in the U.S. each year. We could teach these athletes about health promotion, nutrition and wellness. We could improve the quality of life and perhaps the life expectancy for 175,000 athletes. I think we should set a goal of doing just that and that the U.S. Department of Health and Human Service should assist us in this mission.

Second, all public and private programs, initiatives and reports that address the health needs of the general public should explicitly examine the unique needs of persons with mental retardation.

Third, specific health objectives for persons with mental retardation should be established by the U.S. government, consistent with the overall goals of Healthy People 2010—namely, "to increase quality life years and to reduce the gaps in health status." Public schools are provided with a great opportunity to improve the health of school-aged individuals with mental retardation. By law, public schools are required to provide an Individualized Education Program (IEP) for every child with mental retardation. As part of each IEP, the health needs of children with mental retardation should be assessed and appropriate services accessed.

Finally, the Inspector General of the U.S. Department of Health and Human Services, as well as the Association of State Attorneys General, should evaluate whether the provisions of publicly funded and private health programs are providing equal or equitable protection to persons with disabilities, including those with mental retardation.

Mr. Chairman, on behalf of the one million athletes we serve we look to you for leadership. Your voice is one of the most powerful in all the Congress. Please speak out on the health needs of people with mental retardation. Please fund all of the programs that will help ameliorate the health deficits of this population. We must demand training programs for doctors and other care providers, fund data collection initiatives so that we can better understand prevalence and needs issues, and please, please fund health prevention programs so that people with mental retardation are not dying 10–20 years earlier than the rest of the American population.

I urge everyone to leave this hearing room and visit the Special Olympics Healthy Athlete Clinic at the Eagan Center. Watch an athlete smile as he sees his parents and coach for the first time because he was given a pair of glasses with the right prescription. I promise that you won't see any "down and dirty" treatment at our clinic.

In closing, let me remind policy makers around the world who may read this report, that here in Alaska, we are celebrating the giftedness of people with mental retardation. We will see their gifts as athletes, and we will see their gifts as human beings. We will see down hill skiers, speed skaters, and floor hockey champions. We will see the Zimmerman family—all 16 members of them—who have come here to cheer for Laura Zimmerman who is their sister, daughter, niece, cousin and pride and joy. All of this celebration happens because these athletes were given a chance and when the chance came, oh how they seized the moment!

The lesson here is just that simple: give them a chance. All around the world, people with mental retardation are denied the simplest chance to belong. And yet, they bring gifts as unique as those of any human being. And all they ask is if someone will give them a chance.

May we not leave here without dedicating ourselves to answering, YES!

Thank you.

Senator STEVENS. Thank you very much, Dr. Shriver. I am sorry to tell you that I must conform to the rules of the Senate being a member of the Rules Committee, too. These rules forbid applause at Senate hearings.

Dr. SHRIVER. Now that I am done, that is okay.

Senator STEVENS. I have not had a chance to read the report, of course. What recommendations do you make? Do the people here know what recommendations you have made in this report, beyond what you have just summarized?

Dr. SHRIVER. The report spells out our recommendations with some specificity. Mr. Chairman, I think there really are at least three core recommendations. One is, that data collection has to be improved. The Surgeon General's Office, the Centers for Disease Control, need to create dedicated attention to gathering information about the health status and needs of this population. It is not gathered now, and without data, as you know, it is very difficult to make a case on how important it is for change in the health care system.

Second, I am not an expert on medical care and medical insurance, but the gaps in reimbursement, the gaps in insurance are unconscionable. The fact that we have adults in this population who cannot, unless they save their welfare checks or title 19 reimbursements, unless they save that money, cannot see a dentist, is to me just shocking. I have mentioned this to several people and they shrug their shoulders, senior policy leaders—it is too expensive, we cannot get to it—so people are basically making up their minds to deny this population access to care. That has just got to change.

I think, third, we have to look at the training issues. Too many doctors, 79 percent—one of the pieces of data here, 79 percent of psychiatrists claim that they have no training in the care of people with mental disability. This is the mental health care profession.

Medical schools around the world need to change the curriculum, and we need leadership from the Secretary of Health and Human Services, the Surgeon General, and other leaders in the medical field to demand that the training of medical professionals include attention to the special needs of this population.

Additional recommendations are spelled out in this report, Mr. Chairman. We on our part can contribute to public health through our healthy athletes programs. We are not a health care organization, but we see other organizations providing medical services through vans in communities and cancer screenings and dermatological screenings, these kinds of things, in nontraditional ways. With support from organizations like the Lion's Club and potentially from Government sources, we could screen and offer health screening services to 100,000 or 200,000 athletes a year.

Currently we are not able to do that. We now serve just over 20,000 in our most ambitious projections. We could serve significantly more through the Special Olympics Athletes Program, if we had help.

Senator STEVENS. Well now, you deal, or Special Olympics deals with the fittest of the fit in this population.

Dr. SHRIVER. That is right.

Senator STEVENS. What about the balance of this population?

Dr. SHRIVER. Well, that is the scandal. All the data you have here is from the fittest of the fit. We are trying to do outreach in Native communities and urban populations, and hard-to-reach rural populations, to bring more people into a fitness and sports movement, but until we focus more attention to these needs, we will continue to see obesity, we will continue to see tobacco use, we will see all the neglect issues, that come as a result of people living in settings where no one has seemed to care, and where the medical profession is not an active ally in promoting a healthy lifestyle.

Senator STEVENS. There have been no studies of the impact of diet or substance abuse on people with mental retardation?

Dr. SHRIVER. We have some controlled studies of tobacco use in institutionalized settings, but no community-based or population studies that we are aware of document these issues across the board. I am sure the Surgeon General can speak to these issues much better than I can, but we were not able to find any.

Senator STEVENS. We will hear from Dr. Satcher on our next panel, so thank you very much. Thank you, Cindy.

Ms. BENTLEY. You are welcome.

INTRODUCTION OF DR. SATCHER AND MS. SWENSON

Senator STEVENS. We appreciate it very much.

Dr. Satcher, the Surgeon General of the United States, accompanied by Sue Swenson, Commissioner of the Administration for Developmental Disabilities. Thank you.

For the audience, Dr. David Satcher is the 16th Surgeon General of the United States. He is only the second person in history to simultaneously serve as the Surgeon General and as the Assistant Secretary for Health. Before becoming Surgeon General, Dr. Satcher was the Director of the Centers for Disease Control and Prevention and Administrator of the Agency for Toxic Substances and Disease Registry. He was also the president of Meharry Medical College in Nashville, Tennessee.

Dr. Satcher received his Bachelor of Science degree from Morehouse College and his M.D. and Ph.D. from Case-Western Reserve University.

Also, Ms. Swenson is introduced here. I will do it right now. Sue Swenson is the Commissioner of the Administration for Developmental Disabilities at the U.S. Department of Health and Human Services. She served on the Senate Labor Subcommittee on Disabilities as a Joseph P. Kennedy, Jr. Foundation Fellow, and holds an M.B.A. from the University of Minnesota, as well as an M.A. and a B.A. from the University of Chicago, and is the mother of three sons. We welcome you, too.

Dr. Satcher, please proceed.

STATEMENT OF DAVID SATCHER, M.D., U.S. SURGEON GENERAL, U.S. PUBLIC HEALTH SERVICE, DEPARTMENT OF HEALTH AND HUMAN SERVICES

Dr. SATCHER. Thank you, Senator Stevens. I am delighted to be able to join you and members of the Special Olympic Committee, Mrs. Shriver and members of the family and all these outstanding athletes.

Senator STEVENS. Pardon me, doctor. Can you all hear back there? Pull it right up.

Dr. SATCHER. I will start over. I am very pleased to be here to join you in this very important hearing, and to join all of those who have worked so hard to make the Special Olympics possible, and these outstanding athletes.

As you know, Senator Stevens, I have submitted testimony, so I will just summarize briefly what I have said and respond to any questions or comments.

Senator STEVENS. All of the statements submitted will be printed in the record, and we are glad to have your additional comments.

Dr. SATCHER. I do want to say that in addition to my testimony I have had the opportunity to spend the last 3 days here in Anchorage and on Friday, of course, went out to Emmonak to really see some of our programs in the rural areas of Alaska, and that has been quite eye-opening.

On Saturday I also had an opportunity to have lunch with Tim and some of the mothers of children with mental retardation, and to hear their concerns about medical care in this area, and that also has been very helpful. I had a chance along with Dr. Steve Corbin and others to visit the health screening units on Saturday afternoon, including visual and oral screening, but also for the first time, health promotion. So I have learned a lot since I have been here. I do not come as an expert in this area, but I do come as one who is very concerned about the quality of health and health care that exists in our country for people with mental retardation, and I hope that I can use my position as Surgeon General to make a difference.

I must say, Mr. Chairman, as you know, as Surgeon General I have produced at least three reports that have been different in terms of their attention to areas of neglect. I released the first ever Surgeon General's Report on Mental Health in December 1999. That report dealt extensively with the problems of and made major recommendations with regard to mental health in our country.

The shortcoming of it, of course, was that we did not have quality studies on mental health issues related to people with mental retardation. By the same token, we released the first-ever report on oral health, which included a major section dealing with disabilities and responding to the needs of persons with disabilities. But again, there was no examination of community-based population studies for persons with mental retardation. So even though the report dealt with disabilities, it did not target mental retardation.

By the same token, for the first time, Healthy People 2010 has a full chapter dealing with disabilities, and several objectives that we hope to achieve by the year 2010. Even though we deal with disabilities, however, we did not have the studies to specifically target mental retardation. So we are looking for ways to be more inclusive over the next few years.

So these are the efforts that we have made in the short time we have had. I do want to agree with Dr. Shriver, or Tim, in saying that I think there is a major problem in terms of medical care, and I think it does start with training and sensitivity to the issue of the mentally retarded. We hear a lot from parents and persons with mental retardation, themselves, about their experience in the

health care system. I think we can do better than that, and I think we will do better than that.

I also agree that there are major systems problems in terms of access to care. In our report on oral health, we pointed out the major problem with medicaid reimbursement for dental health care, and that especially affects persons with disabilities.

Many dentists still complain that they virtually have to take money out of their pocket in order to take care of persons, and yet, as you know, the JL report pointed out the shortcomings in medicaid. So there are some major systems problems in terms of physicians and other providers being able to provide the care that is needed. We have to look at the system—we have to look at the training.

I want to close with what I consider to be, I guess you would call them recommendations. They are primarily our view of the way things should be and the way things can be in this area for the future. The first area is education and awareness. We believe that there is a great need for not just the better education of health professionals, but people in general regarding public awareness about persons with mental retardation and their great potential.

I think the Special Olympics has contributed significantly to that effort. But when we try to deal with health problems, if the general population is not aware, just as we said in the mental health report, then a stigma surrounds the problem and that certainly interferes with the provision of care. So we believe that public awareness and better education for professionals is an essential first step in addressing the health needs of persons with mental retardation.

Second, we need population-based surveillance programs. Public health begins and ends with surveillance. Screening programs are great, and I think the screening programs here have been contributing a lot, but it is not population-based surveillance that would really answer the kind of question that you raised about people in the broad population. So hopefully, we can develop those kinds of surveillance programs.

There are 10 leading health indicators in Healthy People 2010, which I hope no one will miss. Five of those are lifestyle, physical activity, overweight and obesity, reducing tobacco use, substance abuse, and responsible sexual behavior. For the next 10 years we are going to really be pushing the American people to reach the objectives in those areas. I believe that there are many people with mental retardation who would benefit tremendously from an increased focus on health promotion and disease prevention in our country.

The second five leading indicators are health systems indicators, starting with access. Again, there are major access problems in this population. I believe that focusing on measurable objectives, in terms of improving access to care, will help persons with mental retardation.

Other leading indicators are mental health, environmental quality, injury and violence prevention, and immunization. So for the first time in these three decades that we have been doing healthy people, we now have 10 leading health indicators that we can follow just as we follow leading economic indicators—not as often—but hopefully at least yearly. And we believe that if we target these

leading health indicators to persons with mental retardation, we can get all of our systems in place with measurable outcomes in these areas. I hope to be a part of that. I certainly believe that the Office of the Surgeon General will be.

PREPARED STATEMENT

And I, like the Special Olympics player, pledge that we really hope to win in this endeavor. But if we cannot win, we should be very brave in our attempt. I believe that we can win, and we hope to win.

[The statement follows:]

PREPARED STATEMENT OF DAVID SATCHER

Senator Stevens and Members of the Committee: I am Dr. David Satcher, U.S. Surgeon General. I am pleased to appear before you today to discuss the need to promote health for people with mental retardation and to go over the findings of a privately funded literature review by Special Olympics, Inc. and Yale University pertaining to the health needs of people with mental retardation. Thank you for this opportunity.

I appreciate the work of the Special Olympics not only for promoting physical activity among individuals with mental retardation but also for providing opportunities for them to develop their talent and performance and for highlighting their unmet health care needs.

THE DATA ON PERSONS WITH MENTAL RETARDATION AND THE LIMITATIONS OF THAT DATA

In the United States, we estimate that the prevalence of mental retardation ranges from 2 to 7.5 million people. Using the 1994 National Health Interview (NHIS) Disability Supplement, Phase I, to identify people with mental retardation or developmental disabilities, researchers estimated mental retardation prevalence of 3.4 percent for the 0–5 age group, 2.5 percent for the 6–18 age group, and .5 percent for those 19 years of age and older.

Worldwide, there are 170 million people with mental retardation, according to World Health Organization estimates. That's nearly 3 percent of the global population.

In the last 40 years, we have witnessed dramatic change in sentiments regarding those with mental retardation. Public policy and practice with regard to the education and treatment of individuals with cognitive limitations began to change in the 1960s and 1970s. Clinical and administrative practices began to reflect empirical findings that learning and improvements in adaptive behavior were enhanced by treatment in less restrictive community-based residential, training, and work environments as opposed to large, overcrowded, and understaffed institutions.

Since the late 1980's the nation's public health system has formally recognized the health needs of people with disabilities and consequently, has developed programs to address their specific health concerns, and has set goals to eliminate health disparities relative to people without disabilities.

Today, mental retardation is diagnosed using three generally accepted criteria: an IQ that is below 70–75; significant limitations existing in two or more adaptive skills areas, such as communications, self-care, functional academics, and home living; and presence of the condition before age 18. Other skills criteria include community use, self-direction, health and safety, leisure and work.

Our ability to fully assess the prevalence of mental retardation in the United States is limited for several reasons:

—We lack a surveillance system that targets the health status and needs of people with mental retardation. Existing survey-based public health surveillance in the United States is inadequate for identifying people with mild cognitive limitations.

—When we launched Healthy People 2010 last year, the nation's health goals and objectives for this decade, it marked the first time we had ever included a full chapter on disabilities. However, due to the limitations in data, we were not able to specifically address the health status, needs and access issues confronting millions of Americans with mental retardation.

—We published the landmark Surgeon General's Report on Mental Health in December 1999. While it offers a comprehensive view of mental health in the

United States based on the best available science and an extensive discussion of mental disorders and problems with stigma and access, it still lacks specific information on persons with mental retardation because of the shortfalls in data.

—Similarly, the Surgeon General's Report on Oral Health provided a sweeping discussion of the oral health needs in this country with a special focus on oral health needs of persons with disabilities; nevertheless, the discussion of the unique needs of persons with mental retardation was limited due to lack of data.

—The Causes/Risk Factors for Mental Retardation

Mental retardation can be caused by any condition that impairs development of the brain before birth, during birth or in the childhood years. Many causes are associated with mental retardation.

It is important to accurately and consistently define mental retardation because of its impact on the prevalence. The most widely used definition comes from the American Association for Mental Retardation (AAMR), which defines mental retardation as the onset of significant limitations in both general intellectual and adaptive functioning during the developmental period, that is, 18 years and under. Although not formally a part of the definition of mental retardation, the APA includes mental retardation in the DSM-IV, classifying it as a mental disorder.

Despite the importance of consistency, mental retardation is not always defined the same way across research studies or service agencies, even within the same state. Some definitions rely solely on IQ scores, others only use adaptive behaviors, while others use a combination of both. Many studies are based on broad categorizations of severity, using labels such as mild, moderate, severe and profound, assigning a corresponding IQ range to each term (mild = 50–55 to 70, moderate = 34–40 to 50–55, severe = 20–25 to 35–40 and profound <20–25.)

The most well-documented approach involves two classifications: cultural/familial and biologic/organic, based on the prevalence or absence of a known organic etiology. Cultural/familial refers to individuals with IQs of 50–70, who do not have any identifiable physiological deficit. They cognitively develop at a slower rate and do not reach the same cognitive levels as the general population.

Those in the organic group have an identifiable physiological deficit and typically have IQs lower than 50, although sometimes individuals with higher IQs in the 50–70 range can be included in this group. It would also include genetic causes such as Down Syndrome.

THE RANGE OF HEALTH PROBLEMS/DISEASES AND CONDITIONS AFFECTING PEOPLE WITH MENTAL RETARDATION

The health issues for individuals with mental retardation are similar to the health issues for many people with disabling conditions, namely, physical activity, nutrition, access to health care, clinical preventive services, oral health, mental health, and family care giving.

While population based data are unavailable, research using samples of convenience have demonstrated that people with mental retardation are at increased risk for obesity, cardiovascular disease, osteoporosis, seizures, mental illness and behavior disorders, hearing and vision problems, and poor conditioning and fitness. Cohort and group effects, such as those related to institutional experience and residential status, are generally poorly controlled.

In 1991, heart disease was the leading cause of death for people with severe mental retardation.

Overweight and obesity levels in this country have reached epidemic proportions. However, people with mental retardation have been reported to be at a much higher risk for obesity than their peers without retardation. In some studies, up to 46 percent of individuals with mild mental retardation were obese. There are genetic causes of mental retardation that are associated with obesity, such as Down Syndrome and Prader-Willi Syndrome.

The type of living arrangement was strongly linked to obesity. Higher percentages of obesity were noted among people in community residential environments. Especially troubling was the finding that 55.3 percent of individuals with mild cognitive limitations residing with their natural families were found to be obese.

These studies also revealed a strong link between obesity and coronary heart disease, cancer, social stigma, and discrimination.

Significantly lower bone mineral density has been reported for a group of people with moderate to mild mental retardation with a mean age of 35 years when compared with age-matched controls.

THE UNIQUE IMPACT OF HEALTH PROBLEMS/DISEASES AND CONDITIONS AFFECTING PEOPLE WITH MENTAL RETARDATION

People with mental retardation face unique health problems resulting in lower life expectancies and lower quality of life.

Life expectancy of people with mental retardation has increased to the extent that younger adults with mental retardation are expected to demonstrate little disparity in longevity; however, for older adults, disparities continue to exist. Specific subpopulations, people with Down syndrome for example, are at increased risk for premature mortality.

A number of studies demonstrate that adults with mental retardation compare unfavorably with their peers without mental retardation in terms of activity, fitness levels, and obesity, resulting in increased risk for disease and poor quality of life, reduced cardiovascular fitness, higher cholesterol levels, reduced muscular strength and endurance, and cardiovascular disease.

As more people with mild cognitive limitations are living in unsupervised environments or are under the occasional care of family members, service coordinators, friends, or other benefactors, there is little opportunity for organized fitness activities specifically targeted at this population.

PEOPLE WITH MENTAL RETARDATION SUFFER DISPROPORTIONATELY FROM LACK OF ACCESS TO APPROPRIATE HEALTH CARE

Health promotion, disease prevention, early detection and universal access to care are the cornerstones of a balanced community health system. Yet, in each of these areas, individuals with mental retardation face barriers.

Research has demonstrated that many primary care providers are unprepared or otherwise are reluctant to provide routine and emergency medical and dental care to people with mental retardation. Many providers refuse to serve, or limit the number of people served under the Medicaid program, a source of coverage for many people with mental retardation. Dental care for adults is a particularly difficult matter in that, by and large, Medicaid does not cover adult dental care.

For example, many health professionals have little exposure to individuals with mental retardation and, as a result, are sometimes uncomfortable treating them. That is tragic, considering that people with mental retardation have been reported to be at higher risk for behavioral and emotional difficulties than the general population, with prevalence ranging from 20–40 percent.

In addition, the medical and dental care of those individuals in community-based residences is no longer obtained from a centralized institutional staff but from primary care providers in the community. Increases in the use of community-based primary health care has not been without difficulty and the decentralization of services has brought with it the need for increased personal responsibility in terms of self-advocacy, self-determination and, in many cases, increased care giving responsibilities by families, often life-long care-giving responsibilities. Care-giving responsibility by families become increasingly difficult as the parents become aged or infirmed.

Special Olympics International (SOI) is to be commended for expanding its "Special Smiles" Program into its new Healthy Athletes Initiative. The Health Athletes Initiative works to improve the overall health of each Special Olympics athlete. Through this initiative SOI is increasing public awareness of the health needs of people with mental retardation, increasing their access to care, and training professionals to care for people with special needs.

The Special Smiles program, initiated in 1993, includes a non-invasive oral exam, brushing and flossing instructions, mouthguard fabrication (at selected sites), provision of oral hygiene products, including toothbrush, toothpaste, and floss, and educational materials. Participating athletes benefit from a referral program designed to link people with special needs with dental professionals who are experienced in providing dental care to patients with mental retardation. Since 1993, over 53,000 athletes have been screened during Special Olympic State Games in 36 States and 2 international sites.

Finally, we must point out that few formal connections exist between public health agencies and educational systems and other agencies that serve people with mild cognitive limitations.

VISION FOR THE FUTURE

The greatest barriers to the improvement in health status for people with mental retardation include stereotypes and negative attitudes among the public, governmental agencies, service providers, and, in some instances, among family members.

Until the early 1970s, public policy emphasized the segregation of people with mental retardation from the rest of the population—first for therapeutic reasons and later for the "protection of society."

While we have overcome many of these barriers, we still have a distance to go before we reach our goal. We believe that the quality of life can be better in the future if we strategically focus our efforts in the following areas:

—Developing and implementing a surveillance system that specifically targets the health status and needs of people with disabilities, including those with mental retardation and other developmental disabilities.

—Providing for Public Health surveillance of people with mental retardation to track prevalence, health status, risk behaviors, quality of life, and comorbid conditions. Such a surveillance program is challenging given that the nature of the condition limits the participation of the informant, people with mental retardation may not have ready access to a telephone, and people reluctant to disclose mental retardation.

—When and where possible, and with measurable objectives, tracking the 10 Leading Health Indicators of Healthy People 2010 specifically for people with mental retardation. The first five indicators are lifestyle indicators: physical activity, overweight and obesity, tobacco use, substance abuse, and responsible sexual behavior. The remaining five are health systems indicators: mental health, injury and violence prevention, environmental quality, immunization, and access to health care.

—Developing and implementing a balanced community-based health system for the mentally retarded. It should balance health promotion, disease prevention, early detection and universal access to care.

—Exploring ways in which the federal government can be more responsive to the unique challenges and needs of people with mental retardation.

—As with other areas of disparity in health, the legal implications of the plight of people with mental retardation needs to be better addressed. We should, therefore, work to protect the legal rights of people with mental retardation.

—The research community should develop a research agenda targeting the problems, needs and opportunities for the mentally retarded. Completion of the human genome project will make it possible to better understand the genetic basis of human development. In addition, it will enable us to better understand the causes that underlie a variety of degenerative and metabolic disorders, including mental retardation.

The theme of the Special Olympics is one that all of us can appreciate—"Let me win, but even if I don't, let me be brave in my attempt." We are all inspired by the sheer determination and persistence we see in the athletes who participate in the Special Olympics and it is out of that spirit that we must forge ahead toward this vision for the future.

I realize these strategies represent high aims, but we owe it—not only to people with mental retardation but to all Americans—to press forward in a brave attempt to reach them.

Senator STEVENS. Thank you very much, Dr. Satcher. Ms. Swenson.

STATEMENT OF SUE SWENSON, COMMISSIONER OF THE ADMINISTRATION FOR DEVELOPMENTAL DISABILITIES, U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

Ms. SWENSON. Senator Stevens and representatives of Senator Specter's office, I am very grateful to have this opportunity to speak to you today. I represent a small program in the Department of Health and Human Services called the Administration on Developmental Disabilities.

Five years before the first Special Olympics Games, Eunice Kennedy Shriver began the program. In partnership with her brother, President Kennedy, and with advice from Dr. Robert Cook, in 1963 she started a small program that would provide university training of professionals working with people who had mental retardation and developmental disabilities. Over the years, we have expanded. I am here today to tell you that there is much more we can do.

I am, sir, a mother of three sons, one of whom has severe mental retardation and developmental disabilities. I have been a consumer of the programs that I am now in charge of. I know how effective they can be. I would like to briefly summarize the programs.

First, every State has a Governor-appointed Developmental Disabilities Council. Ms. Bentley served on our council in Wisconsin.

Second, every State operates a legal clinic called the Protection and Advocacy Agency that ensures that people with developmental disabilities are not abused and neglected.

Finally, every State has at least one university center of excellence in developmental disabilities research training and service delivery. These centers provide community consulting services and training of professionals both before they become professionals and after they are already in practice. We help train them to understand the needs of people with mental retardation. This is a place where we can do much more than we have in the past and the reauthorization that was completed in October 2000 supports that goal.

Last year's reauthorization was bipartisan in nature. There was cooperation between the administration and the Congress, and the resulting legislation positioned us to step up to the plate and do much more than we had in the past. I concur with everyone who has spoken today that access to health care, access to employment, which frequently is a way to get health care, and access to education, which is the way to get employment, are three serious problems that are affecting people with mental retardation.

Part of my job is to go around the country and listen to the concerns of people who have mental retardation and developmental disabilities and their families. I hear that the medical profession is not aware of the needs of people with mental retardation and people with mental retardation have been shut out of the health care system. People with mental retardation and their families, every day in this country, ask for counseling from psychologists and are told there is no hope of feeling better because they have a disability, or their child does.

There are people in this country every day who visit a doctor who does not spend the time or does not know how to explain what they need to know to manage their own health care.

Every day, there are people with fetal alcohol syndrome in this country who are seeking treatment for alcohol abuse, so that they do not pass this disorder on to their own children.

Every day, there are people seeking rape counseling, young women with mental retardation, who want to learn how to protect themselves and are not being encouraged or allowed to find ways to do that.

Every day, there are people, who spend the whole day watching television and cannot even see the television set, because the glasses that they have are the wrong prescription, or they have no prescription, or the staff who work with them do not even understand that it is important to put the glasses on.

Every day in this country we have people who are parents, and they have cognitive disabilities or mental retardation themselves, and when they take their child to the physician, they cannot get instructions to help them understand how to care for their child.

Many of those children end up lost to the child welfare system, rather than being raised by parents who love them dearly.

There is, in my experience, an underground market for information in this country among parents with children with mental retardation and developmental disabilities. We trade the names of physicians who will see us and who are able to understand us as if it were a secret resource. We can do better than that and programs can help do better than that.

PREPARED STATEMENT

We are a pipeline between, if you will, the exploration and the drilling that happens in CDC and NIH and the folks who are living with these disabilities on the street. We can do more and we will. Attention to the special needs of people with mental retardation and the developmentally disabled and to our programs will help. Thank you so much for elevating the level of attention to this area by holding this hearing today.

[The statement follows:]

PREPARED STATEMENT OF SUE SWENSON

Chairman Stevens, Members of the Committee: Thank you for the opportunity to testify today in the beautiful State of Alaska about the health status of people with mental retardation. My name is Sue Swenson and I am the Commissioner of the Administration on Developmental Disabilities (ADD) in the Administration for Children and Families in the Department of Health and Human Services. I am also the mother of three sons, one of whom has multiple disabilities, including cognitive disabilities (mental retardation). I will be speaking today from my experience as Commissioner, but as you know, no mother ever ceases being a mother. Most of what I am addressing is very close to my heart.

THE ADMINISTRATION ON DEVELOPMENTAL DISABILITIES

ADD is a nationwide system of State-based programs designed to help people with developmental disabilities such as mental retardation, live productive, independent, decent, ordinary lives, living in the community and integrated into our American way of life. Local programs funded by ADD are present in all 50 States, the District of Columbia, and the territories of the United States.

The programs are authorized by the Developmental Disabilities Assistance and Bill of Rights Act (The DD Act). The Act was successfully reauthorized in the 106th Congress, and signed by President Clinton on October 30, 2000. The reauthorization was genuinely bi-partisan in both Houses, and reflected a strong partnership between the Administration and the Congress. The Act authorizes the following activities:

—A Governor-appointed Council on Developmental Disabilities (DD Council) in every State and territory. The DD Council includes people with disabilities and their family members, with a special focus on including people who have severe developmental disabilities and their families. It also includes the chief State agencies that are responsible to serve people with developmental disabilities. The Council must track the needs of people with developmental disabilities in a State, plan for service improvements, and make grants and administer programs to test and demonstrate new ideas and service models. The Council is responsible for informing State leaders, including legislators, about the needs of people with developmental disabilities in the State.

—A Protection and Advocacy Agency (P&A) in every State and territory. The P&A offers individual advocacy and legal services to Americans who have severe disabilities and would otherwise be unrepresented. The P&A is responsible for ensuring that individuals with developmental disabilities may be safe and free from harm. It seeks to improve conditions in congregate settings that are unsafe or abusive, and when improvements are not possible, it seeks to close these facilities and move residents to settings that are safer.

—At least one University Center for Excellence in Developmental Disabilities Research, Training and Service is in every State and most territories. Previously known as University Affiliated Programs (UAPs), University Centers for Excel-

lence (UCE) are housed in a university and mandated to work in and with the communities they serve. The goal of the nationwide network is to bring validated, best-practice disability initiatives into community practice in each State. UCEs translate the best of what science has to offer through interdisciplinary research, training activities and service demonstration efforts. UCEs train professionals for leadership positions and direct care workers for community services; work to ensure that systems are designed so that people with developmental disabilities have access to the services and supports they need; conduct research and validate emerging state-of-the-art practices; provide technical assistance to agencies and the community; and disseminate information to individuals with disabilities, families, public and private agencies, and policymakers.

—Projects of National Significance, a program that addresses nationally significant and emergent issues that affect people with developmental disabilities and mental retardation. This program has historically identified emerging issues years before other larger grant programs fund them. Recent projects have focused on finding ways to meet the health care needs of people with mental retardation and developmental disabilities, as well as on housing, employment, and self-advocacy leadership development and self-determination initiatives. Also, Family Support projects are now operating in 40 States and territories.

—With the reauthorization of the DD Act of 2000, two new titles were authorized. Title II, Family Support provides for a program of grants to develop and implement a statewide system of family support services for families of children with disabilities. Family support is a small and fast-growing part of every State's human services budget. It is a cost-effective family-centered service concept that is based on the principle that children should grow up in their own families, while recognizing that families of children with disabilities may need a little help to be able to raise their children at home, and that they are the experts on what that help should be. The other new authority, Title III, is a program for Direct Support Workers Who Assist Individuals with Developmental Disabilities. The program is to develop technology-savvy distance learning-based training programs for direct support workers, and establish in every State scholarships for people working in direct support who are earning college degrees.

PROGRESS IN THE GENERAL STATUS OF AMERICANS WITH MENTAL RETARDATION

People with cognitive disabilities (mental retardation) are leading the way to a time of rapid change in how they are treated by society. Only 40 years ago, most Americans who had the label grew up in very restricted circumstances. People often lived in institutions where the more able cared for the less able, with no pay, and some people lived their lives with no access to their families. To add to the indignity, when these people died, they were buried on the grounds of the institution in unmarked graves or in graves marked only by a number. Families who had children like my son often had no choice other than to institutionalize their child. Families were regularly counseled to "put him away and forget you ever had him." The secrecy surrounding such a decision was often severe, and parents reported to their neighbors that their child had died. Americans who believe that there has never been a person with mental retardation in their family may not have the facts. Like the Rain Man, many people grew up isolated from their families to the extent that even their brothers and sisters didn't know they existed.

It is sometimes thought that these institutions were "hospitals" where people received excellent health care. Many families institutionalized their sons and daughters hoping this was the case. Although some institutions may have reached this ideal, physicians who had lost their licenses to practice medicine on the "outside" administered many. Most people with mental retardation had life expectancies decades shorter than their peers without disabilities. It may be surmised that they received less medical care than their peers did.

Now, people with mental retardation are almost always able to grow up in their families and go to school with other children. Special education and Medicaid have made it possible for people who even have more severe forms of mental retardation—such as my son—to grow up and live where they are loved.

People with mental retardation are becoming more aware of each other, more connected to their regular community and to each other. They are forming "self-advocacy" organizations to help other people with disabilities who may not have families, move out of institutions and to help younger people with cognitive disabilities grow up to be proud of who they are. Many of the self-advocates are people who learned self-esteem and organizational skills through participation in Special Olympics.

In my testimony I will use the term "cognitive disability" to mean what we usually mean by mental retardation—that is, a cognitive disability that occurs during a person's developmental years, before age 18. (Please note that cognitive disabilities may occur later in life as a result of head injuries or problems such as Alzheimer's disease, so not all cognitive disability is the same thing as what is now known as mental retardation).

The Administration on Developmental Disabilities (ADD) is different from the major initiatives undertaken by the Federal government around disability. ADD does not do basic research into the biological causes of disability or into potential cures, though we are quite involved in understanding the social causes and behaviors that can increase a person's chances of experiencing disability.

We are focused on finding ways to help people who already have disabilities live with those disabilities productively and independently, in the communities where they would otherwise live to the greatest extent possible. We are focused on listening and responding to people who have cognitive and developmental disabilities and their families in their own terms, so that improvements we seek to make are perceived as improvements by people who need them.

Developmental disabilities are not the same as cognitive disabilities (or mental retardation). The legislative definition of developmental disability (DD) includes only those people whose cognitive disability or other disability is severe enough to require ongoing coordinated services and supports. There are probably 3 to 4 million Americans with a developmental disability and another 3 million who have milder forms of cognitive disabilities.

It is not necessarily easier to live with milder forms of cognitive disability. For example, no one ever mistakes my son for a non-disabled person, while many people with milder cognitive disabilities must choose whether to tell others—such as doctors or employers—about their disability. In addition, many persons with milder forms of cognitive disability may not even know that their cognitive functioning would classify them as such. Thus, many of the accommodations available to Americans with visible or obvious disabilities are not readily available to persons with mild mental retardation.

Even though the definitions of cognitive and developmental disabilities are different, the needs of people who have them can often be quite similar. Part of my job is to listen to the voices of people with cognitive and developmental disabilities and their parents. Let me share with you what they say about improvements they would like to see:

—I have met countless mothers of children with a full range of disabilities who feel they should be offered help when they reach out for counseling in their churches or from a mental health professional. They tell me they are frequently told there is no hope of feeling better.

—I have met people with cognitive disabilities who want to manage their own health care but they don't understand what a doctor says and they are too sad—or angry—to ask for a clearer explanation.

—I have met people who have Fetal Alcohol Syndrome (FAS) and all of its attendant problems with impulsivity who tell me they wish substance abuse counselors understood their special problems. One lovely young women told me that she thought the fact that no alcoholism counselor talked to her about FAS meant that she was doomed by her mother's drinking to drink herself. She cried when she told me she still wanted children.

—I have met women who have been raped who want to know how to be sure it never happens again—and women who have no hope that they will ever be able to protect themselves.

—I have met people whose day consists of watching television—and they can't see the screen because they have never had a vision exam. Better health care for them would start with knowing that there is a world beyond five feet in front of their face.

—I have met people with cognitive disabilities who have children, and who do not understand instructions the pediatrician or school nurse gives them.

—I have met many parents of children with cognitive and developmental disabilities who trade the names and numbers of physicians and dentists who will see them—or who take Medicaid—as if they were the most important information imaginable. I have heard people say over and over again, everything changes when you find a dentist.

These examples are common problems in every State.

The Administration on Developmental Disabilities is making a difference. For example, ADD projects have:

—Worked with Special Olympics International (SO) Healthy Athletes Program to identify and train optometrists to work with patients with cognitive disabil-

ities—and then create a statewide database of these caring, trained professionals so that people can find someone to examine their eyes.

—Funded Special Olympics to collect and analyze dental data from the Healthy Athletes Program, so that we might have a clearer picture of the need for dental care among people with have cognitive disabilities.

—Developed model wellness programs to understand what it will take to engage people with cognitive and developmental disabilities in being responsible for their health and wellness.

—Developed adaptations for exercise equipment to ensure that it is accessible to people with a wide range of disabilities.

—Developed curricula to help people with cognitive and developmental disabilities, their families and their caregiving staff navigate managed care systems, and distributed the curriculum nationally.

—Trained hundreds of medical and related health professionals to understand the needs of people with cognitive and developmental disabilities. Much more is possible.

—Provided legal support to tens of thousands of people with cognitive and developmental disabilities who did not understand or receive the Medicaid and Medicare benefits that they need to survive and be healthy.

—Worked with sexual violence programs to help them provide counseling to women who have cognitive disabilities—both after they are victims and before, to help them avoid becoming victims.

—Worked with substance abuse programs to help them become accessible and effective so that people with cognitive and developmental disabilities can be successfully treated for drug and alcohol abuse.

The above examples give some idea of the breadth of ADD's efforts. Of particular note in the health arena is the work of our University Centers for Excellence in Developmental Disabilities. For example:

—The Alaska Center provides distance delivery of intensive home-based early intervention for preschoolers with autism; operates a computerized clearinghouse for mental health workers in the DD field; and shares a lead role in a major statewide Fetal Alcohol Syndrome (FAS) project.

—The Arizona Center examines the incidence of autism and other developmental disabilities for CDC. Ongoing population-based review for FAS is also performed for CDC. Both projects are collaborations between the Arizona UCE at the University of Arizona (UA) and the Section of Medical and Molecular Genetics, Department of Pediatrics, UA. Partners in these projects include the Arizona Department of Health Services, the State Division of DD, and many other state agencies and consumer organizations.

—The New Jersey Center with funding from the New Jersey Technology Assistive Resource Program of NJ Protection & Advocacy, Inc. and The Boggs Center-UAP will train future family physicians, special child health coordinators, and others about assistive technology that supports communication and independence.

—The Oregon Center has a Project Disabled and Healthy that promotes healthy lifestyle opportunities for persons with mental retardation. Through workshop training and a buddy system to support implementation, small groups of adult with developmental disabilities in urban and rural communities in Oregon are provided opportunities to learn and practice healthier lifestyles. Areas of change include nutrition, physical activity, alcohol and tobacco use, and stress management. With funding from ADD's PNS health care providers are informed about how to support healthier lifestyles in persons with disabilities who they serve.

The above profiles show how different the Centers are from each other, and how their work complements work of other Centers. The Centers receive administrative care funds from ADD and then receive grants and contracts from State and other Federal funding sources. Each Center responds to the strengths of its host University as well as to the needs of people with developmental and cognitive disabilities in the home State. Each Center must focus on ensuring interdisciplinary training is available to professionals working or being trained in the State.

The 2000 reauthorization of the Developmental Disabilities Act links these efforts together in a nationwide network for the first time. This model is expected to create new knowledge by helping us better manage what we already know. In my professional judgment, the new national network and knowledge management system will bring more change than we have ever seen in the lives of people with developmental and cognitive disabilities. It is our stated goal to ensure that Americans who have developmental and cognitive disabilities are as healthy as their non-disabled peers.

ADD is fundamentally interested in improving the data systems to help our nation understand the health needs of these individuals. We also see that people with

more involved disabilities rely on coordinated and integrated service from many different systems. Data from all of these systems should be integrated. We can then begin to understand that a person who has cognitive disabilities and is unable to drive a car may not be able to get from his or her home or job to a health care professional using public transportation. In this case, a transportation problem is expressed as a health care problem.

Better integrated data systems would also allow us to explore the relationship between the needs of people who grow up with cognitive disabilities and the needs of people who develop cognitive disabilities as a natural part of their aging process or as an expression of Alzheimer's disease. There is much evidence that our society's efforts to include people with disabilities have collateral benefits for many other Americans as well. We know that curb cuts meant to make our neighborhoods and cities accessible to people who use wheelchairs are useful to people pushing baby strollers, as well as to joggers and delivery people. We should expect that improvements in the training of medical and related health professionals will allow them to treat aging Americans experiencing new cognitive limitations as well as people who grew up with cognitive disabilities. In turn, we will all benefit from a more informed health care system.

Senator STEVENS. Thank you very much. I am trying to figure out about our Global Messengers, whether they should continue to sit here the whole time. I think they may want to move around. Feel free to move around, and at the next break here we will move your chairs so you can sit back in the audience, okay?

Dr. Satcher, what about this gap in the basic education of health care providers? How can we attack that? I am not sure Congress can do much about that. That is the medical profession, is it not?

Dr. SATCHER. Yes, it is. I think it is a partnership between the medical profession and the community. Dr. Lane was at the luncheon that we had Saturday and talked about a program at Case-Western Reserve where they actually bring mothers of children with mental retardation into the classroom to talk with students. I think an increase in this partnership between the community that is dealing with this problem and the medical educators is what is needed.

The American Association of Medical Colleges certainly can become involved in helping to improve the curricula of medical schools. We need some models. Maybe the model at Case-Western is one that we should look at and try and get some other schools to adopt. That is not the only school. There are other schools that have made a real attempt to improve the sensitivity and awareness of medical students and residents when it comes to the mentally retarded. What we can do, perhaps, is define—here is what I am planning to do.

It was not in my testimony. I did not make this decision until after my meeting Saturday. I want to have a Surgeon General's workshop on the treatment of persons with mental retardation. I want to bring experts, I want to bring parents, I want to bring persons with mental retardation, I want to bring medical educators, and I want to talk for at least 2 or 3 days about what we know and what we do not know, what research we need to do, and I want to issue a Surgeon General's report on the basis of that.

Now, it is not the typical report that takes 2 years and is based on investigative science. This would be the result of a workshop, the kind of thing we did with action for suicide prevention. That had such a major effect on this country. It was a 3-day meeting that we had in Nevada, as you know, and has had tremendous impact. That is what I decided Saturday—after the luncheon with the

parents—that we can do, and that is what I am going to do. It was not in my testimony. It was not vetted in the Department, but it is my commitment.

Senator STEVENS. That is good. I can remember in my younger days how we spent time traveling all over the country trying to find particular types of systems to deal with my cousin. What about this, from the point of view of special education techniques, is that related to medical care, or is it strictly related just to the education side of our society?

Dr. SATCHER. You mean, is it related to medical education?

Senator STEVENS. I am talking about special education for people with mental retardation, to help develop the full potential of their skills, and their ability to handle jobs, et cetera. Is that part of your side of this, or would it be just education—medical aspects, is what I am saying.

Dr. SATCHER. It is primarily the education side, but that can change, you know. When we did the Children's Mental Health report we worked with the Department of Education and the Department of Justice.

Senator STEVENS. Did you deal with people with PET scans capability, for instance, and run some of the tests for cognitive capability.

Dr. SATCHER. Oh, sure, the technology, definitely, most definitely.

Senator STEVENS. Is there more we should be doing in that area as well?

Dr. SATCHER. I think so. I think in general—and I did not make a point of this. It is in my testimony. I think we need a more balanced research agenda in this area, and all of the things we do not know is because we do not have the research. We have not had people writing proposals for NIH and CDC and other places in these areas, so we need a surveillance system first, and we need more emphasis on the balanced research.

When I say balance, I mean, in addition to basic and biomedical research, we need behavioral research, community-based research, a balanced research agenda in this area as we move into the future.

Senator STEVENS. Ms. Swenson, what does your agency have to do with the education side of people with disabilities?

Ms. SWENSON. About half of our university programs are housed in departments of special education and about half in medical schools, and each have the responsibility for creating interdisciplinary education between people in special education, in medicine, in related fields of medicine such as physical therapy, occupational therapy, and all the related fields.

We would like to be sure that people are getting the kind of interdisciplinary training that really does make a difference for people that have developmental disabilities. So our university program here, for instance, partners with the medical school in Seattle, Washington.

Senator STEVENS. Thank you very much for joining us today, and we will take your comments back to our colleagues and hope that they work with you when we both return to Washington.

Let us take now about a 5-minute break, and I am going to arrange to move these chairs, and give the reporter a 5-minute break.

INTRODUCTION OF MS. PERDUE, MR. JESSEE, AND DR. KLEINFELD

Our next panel is Karen Perdue, Commissioner, Alaska Department of Health and Social Services, Jeff Jessee, Alaska Mental Health Trust Authority, and Judith Kleinfeld, Professor of the University of Alaska.

Karen Perdue, as I said, is our commissioner. She is also a former employee of a very distinguished Senate office.

She serves as aide to Lieutenant Governor Terry Miller, and as Deputy Commissioner of Health and Civil Services. She is a native of Fairbanks and a graduate of Stanford.

Jeff Jessee is executive director of, as I said, of Mental Health Trust Authority. He is a native of Sacramento, California, came to Alaska as a VISTA volunteer, and helped start a nonprofit agency to protect the rights of people with developmental disabilities.

Dr. Judith Kleinfeld, professor of psychology at the University of Alaska, Fairbanks, is Director of the Northern Studies Program. She earned her bachelor's degree from Wellesley and a doctorate from Harvard University. She is the author of several books on children, adolescents, and fetal alcohol syndrome.

Karen.

STATEMENT OF KAREN PERDUE, COMMISSIONER, ALASKA DEPARTMENT OF HEALTH AND SOCIAL SERVICES

Ms. PERDUE. Thank you very much, Mr. Chairman, for the opportunity to talk to you today about mental retardation, developmental disabilities, and health, and I am going to focus a little bit on Alaska in my remarks. I wanted to say that I generally agree with what the speakers have said so far, and embrace the fact that we do have some serious problems, but I would like to also familiarize you and perhaps the rest of the audience with some of the good things that are happening in Alaska, which I think we have to contribute to the Nation and perhaps the world.

When you are talking about persons with severe disabilities, mental retardation, I am happy to report to you that Alaska was one of the first States in the Nation, perhaps the first, to close all institutions for persons who have mental retardation. We have no individuals in Alaska living in institutions who have mental retardation. On November 15, 1997, I was honored to close the last institution that we did have, and perhaps we hold the distinction in the world, as well, in regard to integrating persons with mental retardation and developmental disabilities into our communities.

We followed the individuals who moved Harbor View Developmental Center and talked with them in this audience, and I have to say that without hardly any exception the individuals were happier living in their own homes, or in small homes, and no person has ever asked to go back to an institution since that time.

There were a lot of naysayers, and people who believed that this could not be done, and I have had the opportunity to visit with many of the people who have moved out of our institutions, and I wanted to just give you a story or two about how their health status has improved remarkably since that event.

One woman that we have in Anchorage, her name is Charlene, and she had lived in an ICFMR, an intermediate care facility for the mentally retarded, since she was an infant. She had had significant medical concerns that required weekly visits to the doctor. She struggled to maintain her weight, and was scheduled for surgery to straighten her hand. She had, in talking to her mother, multiple surgeries to untighten her muscles.

She is now 31 years old. She lives with a roommate in a house here in Anchorage. Within weeks of moving into her home, she began to gain weight, her mother told me over 30 pounds, her surgeries were canceled because her muscles began to relax, she began sleeping through the night, and now she has a very active life. She volunteers with the Pioneer Home, attends local arts events, and her family reports she has never been healthier.

We also have over the last decade moved very aggressively to make sure that our young children who have very complex medical conditions do not grow up in hospitals or nursing homes. I wanted to familiarize you with a couple of little kids that I have met, or have had a chance to learn about.

One little boy, his name is Zachary, and he spent his first 5 years of life living at Providence Hospital. His needs were so severe—he was born prematurely—that he was not considered safe to live in a nursing home. He was totally dependent on a ventilator and G-tube. His dad, a single parent, had to quit his job and move from Kenai to Anchorage to be with his son, and he was very, very dedicated to his son.

Today, I am happy to say that Zachary is 13 years old, he lives in the Kenai Peninsula, he attends school full-time, he is not on a ventilator, and he is able to integrate himself and have a rich and full life.

And then finally, it is very fortuitous that Surgeon General Satcher went to Emmonak, because I wanted to tell you the story about Tyler. Tyler was a 7-year-old boy who was ventilator-dependent and fed through a G-tube, and he returned to his home in southwest Alaska just in the last 2 years. He lives in a community with no doctors and no hospitals. It has taken a tremendous commitment on the part of medical personnel, nurses, and our other staff in Alaska to allow these stories to be successful.

Medicaid has been very useful. Five years ago, we only had 10 children in Alaska using our medicaid waiver for children to support them in their communities and their homes. Today, we have over 100, and we expect to double that amount in the next few years.

Likewise, for adults with mental retardation and development disabilities, we have almost 3,000 people now using medicaid waivers for support, and living in the community, so because of this dramatic change of philosophy, Alaska actually ranks the very best in the Nation in terms of the number of people who do not live in institutions.

I think we do have some important and very good experts from our service providers, our university affiliated programs and our DD Planning Council that can offer national expertise on some of these issues, but we do have problems, and I would like to address some of those in my time remaining.

People who have developmental disabilities have a difficult time finding employment, and most of them want to work, and one of the things that we find is that the medical coverage, if a person takes a job and is very ill, and they do not have medical coverage, it is a very bad dilemma for them.

The medicaid program has been difficult to work with so that people can maintain their medicaid coverage and also work. Alaska was one of the first States to use a medicaid buy-in program to help persons with developmental disabilities maintain their medical coverage, but more could be done in this area.

I am sorry to say that oral health is a serious problem here in Alaska as well. We do not have good medical coverage under the medicaid program for adults for oral health care. In fact, it is pretty dismal, and because of that, because of the medications they take, their gums can easily deteriorate and have serious medical problems that affect their whole body, and what we find is, people actually have their teeth removed or pulled because they cannot be saved because they do not have access to preventive medical care. We have had some donated dental programs. We have had some attempts to ameliorate the situation, but the coverage under medicaid is not good.

The challenge of obesity, as mentioned earlier, is a problem for Alaska. In 1990, we had about 25 percent of our Alaskans were overweight, and I am sorry to say almost 40 percent are today, and we do not see much difference between that in the general population and the developmentally disabled population, and I think that is a very important area of concern.

You have provided us with support in Alaska for our Take Heart Coalition and our Eat Smart Coalition, and I think we could be doing more with those efforts in regard to specific concerns raised today.

Then I wanted to address one other area that I think is extremely important. We have a very excellent program in Alaska, Senator, called the Infant Learning Program, and what the Infant Learning Program does is, it takes babies and toddlers, infants and toddlers who are experiencing delays, whether those are motor delays, speech, vision, hearing delays, and works with them intensively. It gives them a multidisciplinary assessment with experts, and assigns therapy people who usually come into the child's home and work with the parents, work with the infant to really get in there and see if a difference can be made in these crucial developmental windows.

Alaska has had an Infant Learning Program for many, many years, but I am sorry to say today that there is a waiting list for this program, and what is happening is, the Federal Government gives us some support, about $1.6 million, and the State puts in another $4 million, and we serve the most severely delayed children, those children who have a 50-percent delay.

What is so heartbreaking for infant learning teachers and programs is that it often is true that we can have the most difference with the children with the lesser delays, but yet they are on the waiting list, and an infant on a waiting list is a pretty difficult thing to think about, so we have about 300 infants waiting for help under that program.

Just two other things quickly I wanted to mention. One is, training for personnel that work with staff, both health care workers, as has been mentioned, and direct service workers. These are desperate needs that we have in Alaska for not only the training, but the kinds of recruitment and salaries that people are needing to work with these populations, because it is very important that they get the very best, most sensitive care possible.

To conclude, I want to thank you for your support for our State's FAS efforts. We are starting to see real community activity now on the prevention of FAS, as a leading cause of preventable mental retardation in Alaska. We have nine community teams mobilized across the State, and we have many, many projects going on, and I think that we are going to see benefits from this for years to come.

PREPARED STATEMENT

Senator, thank you. We stand ready, as Alaskans, to assist in any way that is necessary with this national effort, with the Surgeon General, with Special Olympics. Thank you very much for inviting us here today.

[The statement follows:]

PREPARED STATEMENT OF KAREN PERDUE

Good morning Senator Stevens, members of the Senate Committee on Appropriations. I am honored to be here today and to provide testimony on ways we can promote health for people with developmental disabilities, including mental retardation.

Alaskans with developmental disabilities want the same things that all Alaskans want: access to quality health care, learning opportunities, opportunity for self-determination, suitable transportation, employment opportunities, and ability to take part in community life.

Alaska is deeply enriched by the participation of its developmentally disabled citizens in community life and concomitantly, persons with developmental disabilities tend to live healthier, fuller lives when they live in their own homes and participate fully in the community.

Gone are the days when persons with mental retardation or developmental disabilities live in institutions where they are not accorded the simple freedom of living like you or me. More and more services are being provided in locations where people with disabilities live, work, learn and play. For the most part, Alaskans with developmental disabilities no longer have to leave their home communities to receive the supports they need to live with dignity.

My department tracks and works to prevent birth defects that are related to developmental disabilities. But we also recognize that people with developmental disabilities are special and valuable members of society who bring special strengths to the community. As an agency, we embrace our mission of providing people with disabilities with services that support their full and healthy integration into community life.

I have reviewed the reports prepared for this committee on the health status and the needs of individuals with mental retardation. In general, I believe the report outlines well the health challenges faced by persons with mental retardation in our State, and its recommendations for policy improvements are sound. I would like to use my testimony to underscore some of the health status and delivery challenges we face in Alaska. Just as importantly, I would like to highlight some of the major improvements we have made in Alaska in providing services and improving the health status of our Alaskan citizens with mental retardation and developmental disabilities. I believe we have much to share with the rest of our nation on this subject.

THE INCIDENCE OF DEVELOPMENTAL DISABILITIES IN ALASKA

There are approximately 11,000 to 18,000 Alaskans with developmental disabilities in Alaska. Eleven thousand one hundred and ninety-six Alaskans are officially

known to have developmental disabilities, but we know that the number of Alaskans with mental retardation is actually much greater, since the definition of "developmental disabilities" tends to exclude people with mild mental retardation. Approximately 3 percent of Alaskans have some form of mental retardation (the vast majority of these are mildly mentally retarded). This equates to approximately 18,660 people in Alaska that we strive to serve through programs for the developmentally disabled.

We use the Alaska Birth Defects Registry to collect and analyze information received from health care providers on babies born with reportable birth defects statewide, including children prenatally exposed to alcohol.

In Alaska, according to the ABDR:

—The incidence of Fetal Alcohol Syndrome is the highest of any state in the United States. Fetal Alcohol Syndrome is the leading known preventable cause of mental retardation.

—Of the average 10,000 births that occur every year, approximately 1,600 children are reported yearly with any reportable birth defect.

—Over 4 percent of the 10,000 children born every year (that is, over 400 children) are reported to have at least one major birth defect (major birth defects are those that adversely affect a child's health or development.)

ALASKA DOES IT RIGHT: A COMMITMENT TO COMMUNITY INCLUSION AND INTEGRATION

For over a decade, Alaska has been making a major commitment to integrating persons with developmental disabilities into their communities, keeping people in their own homes—whether that be a medically fragile child or an adult, whether in a small village in northwest Alaska or in our major cities. In my opinion, there is no other single thing that can or has lead to more dramatic health improvements or increased life expectancy than community integration.

Alaska became one of the first states in the nation to close all institutions built for persons with developmental disabilities. On November 15, 1997 I had the honor of closing Harborview Developmental Center in Valdez, Alaska, after 36 years of operation as our state institution for people with developmental disabilities. Residents who had spent literally decades institutionalized, many of whom had profound retardation, now live in small group homes, or in their own supervised apartments. During the same time period, Hope Community Resources closed their institutions here in Anchorage as well.

In a 1998 study that followed up those released from care at Harborview, former residents and their families/guardians reported that they are getting most of the services and supports they need to live in the community.

QUALITY OF LIFE IN THE COMMUNITY

Quality of life indicator	Response	Former residents (percent)	Family/ guardians (percent)
When goals are set for you do people	Help you reach them	95.5	80.0
Feel safe in your neighborhood?	Very safe	81.8	58.8
Do you do fun things in the community?	Yes	72.7	64.7
Are you happy with where you live?	Very happy	68.2	64.7
Do staff help you be part of your community?	Yes	68.2	66.7
Transportation if you want to go somewhere?	Most of the time	68.2	93.3
Do you get the services you need?	Yes	63.6	82.3
Do you feel lonely?	No, not often	59.1	69.2
Feel like an important part of your family?	Yes	45.5	58.3
How do your neighbors treat you?	Very good	40.9	42.9
Choice in job/what you do most days?	Yes	35.0	38.5
Do you have a job?	Yes	22.7	25.0
Choice in who you live with?	A lot	18.2	28.6
Do friends come over to visit your home?	Often	9.1	15.4

Key informants were asked if the closure had a positive or negative impact on the lives of former residents of the facility. None of the key informants said that the impact was negative (75 percent said it was positive).[1] Most importantly, no family

[1] Attachment 1: A Study of the Impact of Deinstitutionalization on the Former Residents of Harborview Developmental Center, Governor's Council on Disabilities and Special Education, August 1998.

member, guardian or resident of these institutions has ever asked to return to an institutional setting.

A study done by Dr. Browner of Anchorage lent additional support for the idea that integrating those with developmental disabilities into the community has positive results on people's health and well-being. He studied 50 Alaskans who transitioned from an institution into 2- to 4-person community homes. These individuals had experienced significant chronic medical conditions and psychiatric illness. The data revealed that when these people moved into community homes, the number of work/home absences, the incidence of accessing medical care, the number of hospitalization days, and the number and frequency of medical therapies all decreased, resulting in overall savings.

I have had the opportunity to know and visit with many of the individuals who moved out of these facilities. I truly believe that their health status has improved, their life expectancy has been prolonged, and their lives have been enriched. While many warned us that drastic results would ensue, the opposite has been true.

I had the opportunity to meet a young Anchorage woman, Shawneen, who had lived in an ICF–MR since she was an infant.[2] She had significant medical concerns that required weekly interventions. She struggled to maintain her weight, and was scheduled for a significant surgery to straighten her hands due to tightening muscles related to cerebral palsy. At 31, this young lady now lives with a roommate in her own home in Anchorage. Within weeks of moving to a more calm setting, she began to gain weight—her mother told me over thirty pounds. Her surgery was canceled as her muscles relaxed on their own. For the first time in her life, she began sleeping through the night. She now has the active life of a young person, attending local arts activities and volunteering at the Pioneer Home. Her family reports she has never been healthier.

I also had the opportunity to visit the last two residents to leave Harborview Developmental Center. I visited them in their new home in Kenai. Both men were near fifty when they left institutional living. They had both lived in facilities inside and outside Alaska all their lives. It was predicted that they would never be able to live in a community setting. Both experienced mental retardation and mental illness. One of the gentlemen experienced water intoxication—the uncontrollable drinking of liquids. Yet, with the right supports, he was able to live in his own home with a kitchen, and to dine out. He was reunited with his mother, visiting her in her nursing home.

Young Alaskan children who had complex medical conditions used to grow up in hospitals or nursing homes. Today, very few children in Alaska are growing up in a hospital or nursing home, even if they have very complex medical conditions. Our service providers are so convinced that health and well-being outcomes are better when people with disabilities live in the community and with their families, that they have adopted the attitude "whatever it takes" to maintain a person in their own community or family setting.

One little boy I have met, Zachary, spent his first five years of life living in Providence Hospital.[3] He was born prematurely and was considered so severe medically that a nursing home was not considered appropriate to care for him. He was totally dependent on a ventilator. His dad, a single parent, moved to Anchorage to be with him. Today I am happy to say this 13 year-old boy lives with his dad at home on the Kenai Peninsula. He attends school full-time and he no longer uses a ventilator full-time. While he has speech and cognitive delays due to his disability, he has a full-time aide to help him at school, and he is living a rich and full life.

Recently, Tyler, a seven year-old boy who was ventilator-dependent and fed through a g-tube returned home to his village in southwest Alaska free of both his ventilator and his g-tube.[4] While he spent his first five years in a medical foster home in Anchorage, our nurses, other medical professionals and service providers worked diligently with his family to prepare for the day when this little boy could join his brothers and sisters back home. This involved many trips for his family and other village caregivers to Anchorage to prepare for the day that he could successfully live in a village of 300 people with no hospitals or doctors.

Families are willing and able to support their loved ones if they have the proper support. Medicaid waivers have allowed the State of Alaska to provider the proper support to make community living possible.

Five years ago, ten children in Alaska were using the Medicaid waiver for Children with Complex Medical Conditions. Today, over 100 children are living better lives in their own homes because of this help. We expect over 100 more children

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[2] Attachment 2. Report on Shawneen.
[3] Attachment 3: Report on Zachary.
[4] Attachment 4. Report on Tyler.

to enter this program as we can develop the trained medical personnel to support the families, and as we carefully prepare families with the support they need to care for their children.

Likewise, Alaska has made aggressive use of other home and community-based waivers for persons with disabilities under Medicaid. Home and community-based waivers began in our State in 1993. Today, 2,853 people are receiving supports through this program, at an investment of over $50 million. Seven hundred and thirty-six people with developmental disabilities receive waiver services. The investment is sizable and will continue to grow as we streamline services, but the cost is less than what would have been incurred if children were growing up in institutions or if adults still spent their entire lives in institutional settings.

HOW DOES ALASKA RANK NATIONALLY?

This dramatic change in philosophy has put Alaska at the forefront of the use of community living over institutional care for the developmentally disabled and other populations. Alaska now has the lowest ratio of nursing home beds to population of all fifty states and the highest ratio of residential beds to nursing home beds as well. Alaska is one of six states with the lowest per capita utilization of nursing homes for individuals with developmental disabilities (10 persons).

Community services have proved very popular, because they meet the needs of families. This has resulted in a waiting list for services and an inability of the system to meet recruitment, training and other personnel needs to provide high quality services.

Although we do our best to serve the needs of Alaska's developmentally disabled population, we recognize that there are more people waiting for our services than we have the resources to serve. Currently there are nearly 1,100 adults and children waiting for DD services. Approximately 400 more individuals were taken off the waiting list last year, but they were replaced by others needing service.

New funds invested in the system since 1992 have been linked to reducing wait lists by serving more people. Little money has gone to cost increases to improve quality or keep up with the cost of doing business. Without systematic increases to pay for uncontrollable costs to providers—such as insurance, increases in the minimum wage, and changes in care needs for an aging population—the quality of services and the basic health and safety of persons served are in jeopardy.

Early Intervention.—Alaska has long-recognized the value of early intervention services for infants and toddlers. Long before there was federal support through the Part C section of IDEA, Alaska created the Infant Learning Program, which provides crucial therapies and interventions for babies and toddlers who are experiencing speech, language, hearing and other delays. Very often, if children can be helped during crucial developmental windows, lifelong developmental delays can be mitigated.

WE ASK THE APPROPRIATIONS COMMITTEE TO CONSIDER SEVERAL KEY ISSUES

Helping persons with developmental disabilities get and keep a job.—Most people with developmental disabilities work or want to work. But there are major barriers that keep people with significant disabilities from working. Most relevant among these barriers is the loss of health insurance. Medicaid is a major source of health insurance for persons with disabilities and for persons with significant medical needs. The loss of Medicaid through increased earnings can be very serious. Alaska was one of the first states to take advantage of the recent Medicaid Buy-In program, which allows persons with disabilities who are working to maintain their Medicaid coverage.

We have launched the Alaska Works program to improve policies that promote work. Through the Alaska Works program, we are striving to improve Alaska's current Medicaid buy-in and to ensure an array of Medicaid services that most directly support working Alaskans with disabilities. We want to enhance Alaska's Medicaid programs to better meet the needs of working people with disabilities and to complement existing Alaska Works activities to address the major barriers that keep people with significant disabilities from working.

Improving oral health.—Persons with developmental disabilities in Alaska have significant oral health problems. Many of the medications that are necessary to control medical conditions common to persons with disabilities contribute to deterioration of gums and dental health. Self care is often not possible. Medicaid in Alaska does not adequately cover preventative dental care for adults, although children's coverage is available.

Dental access is further compromised by the fact that many dental professionals are not adequately trained to provide care that is sensitive to the fears and dental

conditions of persons with developmental disabilities. Alaska would benefit from better dental coverage, and more training aimed at dealing with the special oral health needs of disabled populations.

Responding to the challenge of obesity and overweight.—Obesity is a growing problem in Alaska. The prevalance of overweight adults has grown in the last decade from 25 percent of the population in 1991 to 38 percent in 1999. Alaska has not met its Healthy Alaskans 2000 goal of 20 percent and exceeds the national average. Like all Alaskans, persons with disabilities need appropriate interventions to promote healthy eating and exercise. Alaska-based coalitions like Eat Smart Alaska and Take Heart Alaska are promoting community-based efforts to address these issues. Take Heart Alaska has received federal support through the efforts of Senator Ted Stevens. Specific strategies and programs, including the expertise developed by Alaskans through involvement in Special Olympics, should be used to develop appropriate physical fitness interventions for Alaskans with developmental disabilities.

Increasing support for Early Intervention.—It is critical for children and families to receive early intervention services and support. Funding under Part C of the Individuals with Disabilities Education Act is crucial to our efforts. We support reauthorization of IDEA and continued examination of Part C of the law.

Alaska has used $1.8 million allocated last year to us under Part C to provide comprehensive early intervention services for qualified children. Alaska provides another $4.7 million in State funds. This $5.8 million funds the Alaska Infant Learning Program. Our services include outreach to parents (to find children ages zero to three in need of assistance), screening, evaluation to determine the nature and significance of a child's delays, and assessment of the child's eligibility for further services. Part C dollars are also used to pay for the therapies and services a child needs. Last year, we served 1,600 infants and toddlers.

Most commonly, we get referrals from doctors and parents concerned about their child's development. Parents report an extremely high satisfaction rate with these services. The program not only provides individually tailored help for the child, usually in the home, but also works with parents to help them understand what is occurring for their child and how they can be involved in improving their child's development. The most consistent complaint we get about the program is that parents would like more support and for periods longer than up through age two. The 19 community agencies that deliver these services do an excellent job.

More funding is desperately needed. Right now, children who experience a significant delay of more than 50 percent in speech, language, hearing, or motor skills are prioritized for service. Over 300 children with slightly less delay than 50 percent are on a waiting list for therapy services. This is a heartbreaking experience. These children are often the ones for which intervention will be most effective. A child who experiences a hearing delay as an infant may develop significant speech problems during crucial developmental windows which could lead to learning problems later.

Early intervention services are some of the most cost-effective investments that can be made for children who experience developmental delays. Not providing these services has profound implications for the national and state agenda of improving educational performance for all children. Children must have these building blocks of hearing, speech, language and motor development to be able to reach the school house door with their maximum potential for learning intact.

Alaska is also experiencing a shortage of trained therapists needed to effectively work with these children. Much needs to be done to increase the pay and support for early intervention teachers and to make services available more frequently in rural areas.

Increasing recruitment and retention efforts.—As more people with developmental disabilities are being integrated into our communities, they need support both natural and paid. We are concerned about a growing shortage in the number of qualified health care workers available in Alaska to serve the needs of the developmentally disabled. It takes a targeted effort to bring qualified workers who can respond to the special needs of the developmentally disabled into the work force. We ask for your Committee's help in assessing and understanding the significant role that this shortage could play in creating a crisis of service to the developmentally disabled over the next decade. We ask that this Committee consider taking steps to reduce the shortage.

Health care workers, particularly nurses and occupational, speech and language therapists, play a strong role in the development of treatment plans for the developmentally disabled. The nationwide shortage of nurses is well documented. Recruitment and retention challenges are pressing issues that must be addressed in order to ensure the maintenance of safe, quality services in the community for Alaskans with developmental disabilities.

Direct service workers make the difference on a daily basis in the quality of life for a person with disabilities who needs supports. These jobs are good for our communities as well, in that they provide solid employment in every community in Alaska, rural and urban.

The Alaska Governor's Council on Disabilities and Special Education made several general recommendations about ways to address these challenges. Their recommendations include strategies related to comparable wages and benefits, recruitment, retention, education and training, and efficiency and productivity.

In a recent study that has been provided as back up to my testimony, all 28 Developmental Disabilities (DD) Service Providers in Alaska reported difficulties recruiting and retaining new workers.[5] The survey shows the following:

—Recruitment and retention costs are large and growing. Respondents reported spending $28,112 in advertising to recruit new workers in the first half of fiscal year 1998.

—Survey respondents paid 34,683 hours of overtime during this same time period to cover shift vacancies due to unfilled positions. This translates into an estimated 84,446 hours annually, statewide and an estimated statewide annualized cost of $724,542 in overtime expenditures (beyond the straight time expenses).

—Direct service worker positions were vacant for an average of four weeks before being filled. When positions were advertised, the average agency received eight applications. However, the number of applicants who were actually qualified was only 50 percent. These findings suggest there is a need for a targeted, systemic workforce development plan to address challenges facing the DD service delivery system.

—A majority of respondents reported a number of major problems, which included: finding qualified direct service workers (82 percent); wage and hour considerations (70 percent); direct service worker turnover (68 percent); and staff training and development (65 percent). The top three recruitment barriers or disincentives reported were compensation and pay (81 percent), hours of work (76 percent) and lack of qualified applicants (70 percent).

Mr. Chairman, many of our communities need these jobs and our citizens need these services. Attention to solving these personnel problems can have multiple benefits. We ask the Committee's help as we strive to meet the challenges of recruiting, training, and retaining qualified direct care and health care professionals.

Continuing to support the State's FAS efforts.—Senator Stevens, with your support Alaska is the grateful recipient of a 5-year, $29 million grant from the federal Substance Abuse and Mental Health Services Administration (SAMHSA). We are using these funds to undertake a comprehensive, integrated effort to prevent alcohol-related birth defects, reach out to high-risk women and families, screen and diagnose children at high risk of FAS and alcohol-related birth defects, and improve service delivery to families and individuals already experiencing alcohol-related birth defects. These projects are multidisciplinary, culturally appropriate, and community-based. We are working with schools, doctors, judges, social workers, parents and community leaders to understand how to prevent FAS/FAE, but just as importantly to improve the potential of individuals who live in Alaska who experience FAS/FAE disabilities. Program highlights include:

—Nine Alaskan communities have developed FAS Multidisciplinary Community Teams, receiving training at the University of Washington in identification and diagnosis. Communities include: Bethel, Copper Center, Dillingham, Kenai, Fairbanks, Kodiak, Barrow and Anchorage (two teams). Teams in Nome and Ketchikan will be trained in September. Through this process, 11 medical doctors across our state have been specially trained in how to do an FAS diagnosis.

—Six of the nine FAS Teams have received Team Development grants to assist in getting their teams developed and operating over the next five years.

—Twenty-two community agencies from across the state have received Innovative Community grant funds to develop prevention or service delivery projects in their communities.

—A multidisciplinary training curriculum is currently being developed to provide training to service providers across the state: social workers, youth workers, residential care providers, foster parents, correctional officers, educators and child care providers, public assistance and job training workers, rural health providers and others.

—In November 2001, the state will launch a statewide FAS multi-strategy public awareness/public education campaign.

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[5] Attachment 5: Developmental Disabilities Direct Service Worker Study Results and Findings, Governor's Council on Disabilities and Special Education, October 8, 1998.

Mr. Chairman, I have used my time to touch on just a few of the major concerns that we have in our state regarding the health status of persons with mental retardation and developmental disabilities. While we have many challenges, I also want to underscore that Alaska is an increasingly positive place for persons with disabilities. In many respects, we lead the nation in terms of services we provide to support persons with disabilities and their families. On this very special day in which we celebrate the kick-off of the Special Olympics in our state, it is important to both examine our successes and the challenges we have in front of us. Thank you so much for sponsoring this forum today.

ATTACHMENTS

1. A Study of the Impact of Deinstitutionalization on the Former Residents of Harborview Developmental Center, Governor's Council on Disabilities and Special Education, August 1998.
2. Report on Shawneen.
3. Report on Zachary.
4. Report on Tyler.
5. Developmental Disabilities Direct Service Worker Study Results and Findings, Governor's Council on Disabilities and Special Education, October 8, 1998.

ATTACHMENT 1.—A STUDY OF THE IMPACT OF DEINSTITUTIONALIZATION ON THE FORMER RESIDENTS OF HARBORVIEW DEVELOPMENTAL CENTER, GOVERNOR'S COUNCIL ON DISABILITIES AND SPECIAL EDUCATION, AUGUST 1998

EXECUTIVE SUMMARY

Since its formation in the late 1970's, the Governor's Council on Disabilities and Special Education advocated for the transfer of people living at Harborview Developmental Center to community programs. The Council and other advocates maintained that community services cost less than institutional care, the quality of life of people is better in the community, and the community based services system had the resources to provide support to Harborview residents. Now that Harborview has closed, the Council is conducting a study to determine whether the closure was in the best interest of the people who were living there.

The Harborview Study included interviews with former residents, a survey of family members and guardians, interviews with key informants, and an analysis of the economic impact of the transfer of Harborview Developmental Center residents to community programs. Major findings were:

—Between 1961, when Harborview opened, and 1997 when it closed, 344 people were admitted to the facility. The population at Harborview reached its peak in 1972 when 130 people lived there.

—Former residents, families/guardians and community service providers felt that the Division of Mental Health and Developmental Disabilities provided adequate support during the transition of Harborview residents to community programs. Former residents reported (77.8 percent) that they felt that their needs and wants were considered during the transition from HDC. All of the family members and guardians (100 percent) responding to the survey said that their views were considered during the transition process.

—While many family members or guardians were initially skeptical, most are now pleased with their family member's new lifestyle and the positive changes they have seen.

—Former residents and their guardians rated the former residents' quality of life highly in most areas. Areas that are problematic are employment and integration into the community.

—Former residents and guardians reported that community based services are meeting their wants and needs. Employment services are the greatest need. Most of former residents (77.8 percent) do not have jobs.

—The cost of care in the community ($94,878, including Adult Public Assistance and Food Stamps) is significantly less than the costs at Harborview ($164,000). The net saving equals $69,122 per person.

The study also identified a number of system's issues:

—Most (77.3 percent) of the former HDC residents do not have jobs. Many others in community programs are also waiting for supported employment services. Without additional resources for employment services, this will continue to be an issue.

—There is still work to be done in providing consumers with real choices and integrating them into their communities. These are values that are widely held by

community programs. They are also the values that are most difficult attain. While it is clear that programs are getting former residents out into the community, the challenge will be to support consumers in establishing individual relationships.

—Staff turnover negatively impacts family and guardian confidence in community services. Low wages and lack of benefits cause high turnover and a perceived lack of consistent and professional care.

INTRODUCTION

In the mid-1990s, the Alaska Department of Health and Social Services made the decision to phase out Harborview Developmental Center (HDC). The three-year closure plan was the collaborative effort of many state and community agencies. These included the Alaska State Legislature, the Governor's Council on Disabilities and Special Education, the Alaska Developmental Disabilities Providers Association, the Disability Law Center and consumer advocates, consumers and families, the Alaska Mental Health Trust Authority, the Department of Health and Social Services, and Division of Mental Health and Developmental Disabilities (DMHDD).

Harborview Developmental Center closed its doors on November 15, 1997 after 36 years as the only state-run institution for Alaskans with developmental disabilities. People who had spent much of their lives at Harborview Developmental Center are now living in small group homes, their own supervised apartments or, for some of the older individuals, in nursing homes.

Since its formation in the late 1970's, the Governor's Council on Disabilities and Special Education advocated for the transfer of people living at Harborview Developmental Center to community programs. The council and other advocates maintained that community services cost less than institutional care, the quality of life of people is better in the community, and the community based services system had the resources to provide support to Harborview residents. Now that Harborview has finally closed, the Council is conducting a study to test these assumptions and to determine how those who left Harborview in the past ten years are faring in the community.

The central question explored in the study is whether the closure of Harborview Developmental Center was in the best interest of the people who were living there. A number of issues relating to the closure are explored in this report. They include the:

—transition process from HDC to the community for former residents, families and guardians and community service providers
—quality of life of former HDC residents in the community
—capacity of the community services system to meet the needs of former HDC residents
—permanence of community services
—economic impact of the HDC closure

STUDY METHODOLOGY

Information Insights used a number of research methods to gather information for this report. Interviews were conducted with former residents and key informants, and family members or guardians of former residents received a mail-in questionnaire. The key informants included representatives from the Division of Mental Health and Developmental Disabilities and other state agencies involved in the closure, community services providers, and advocates.

Information on the cost of services at HDC and in the community was gathered from the Department of Health and Social Services. The Division of Mental Health and Developmental Disabilities provided a list of all those admitted to Harborview since it opened in the 1960s.

The project sample was limited to those discharged from Harborview in the past ten years. Because Information Insights could not contact former residents and family/guardians directly, community programs provided assistance by sending out surveys and interview interest/permission forms for the former residents for whom they provide services and supports. Of the 99 people discharged form Harborview between January 1, 1987 and November 15, 1997, 18 had died and 12 could not be located. According to DMHDD records and subsequent follow-up by Information Insights, it was determined that former residents of HDC were discharged to and/or are currently receiving serves from the following agencies:

Alaska Psychiatric Institute—Anchorage
Anchorage Pioneer's Home—Anchorage
ARCA—Anchorage
ASETS—Anchorage

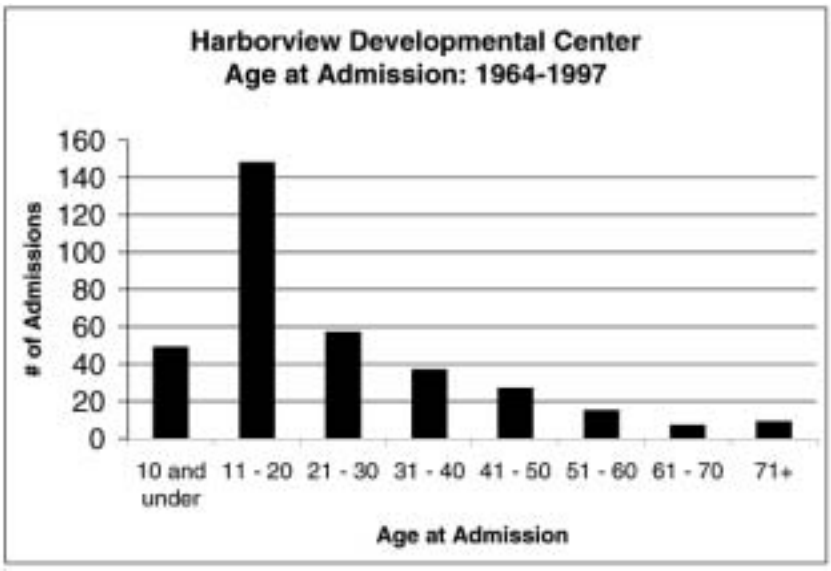
Bethel Community Services—Bethel
Community Connections—Ketchikan
Deaf Community Services—Fairbanks
Denali Center Nursing Home—Fairbanks
Fairbanks Resource Agency—Fairbanks
Frontier Community Services—Soldotna
Hope Cottages—Anchorage
Horizons Unlimited—Valdez
Ketchikan Pioneer's Home—Ketchikan
Kodiak Island Mental Health Center—Kodiak
Mat-Su Services for Children and Adults—Wasilla
Our Lady of Compassion Care Center—Anchorage
Assisted Living Homes—Anchorage
Foster Homes—Anchorage/Valdez

Information Insights interviewed 22 former residents and 16 key informants, and received completed surveys from 18 family members or guardians of former residents.

THE PEOPLE WHO LIVED AT HARBORVIEW DEVELOPMENTAL CENTER

Harborview opened in 1961 as the state's institution for people with developmental disabilities. Prior to this time, any child or adult needing more care than their family could provide were sent to Morningside Hospital and Baby Louise Haven in Oregon. Alaska offered no community care, even for people with less severe disabilities. The 1964 Good Friday earthquake destroyed the original Harborview along with the rest of the community of Valdez. The current Harborview Developmental Center facility was constructed with federal assistance after the earthquake.

Between 1964 and 1997, 344 people were admitted to Harborview Developmental Center. Harborview was at its peak in 1972 when it housed 130 residents. Of the 344 people who lived at HDC over the years, 236 (69 percent) were male and 108 (31 percent) were female. More than half (57 percent) of those admitted were 19 or younger.



Harborview served primarily as a facility for children and young adults with developmental disabilities during the first two decades of existence. The average age of those admitted through 1986 was 19.0 years. This group of HDC residents spent an average of 19.1 years living at the Valdez facility.

By 1986, the number of people with developmental disabilities living at HDC was dropping as programs were developed in the community. In August 1986, the Sourdough Unit was opened to serve people who had behavioral problems that made

placement at other facilities, in particular nursing homes, difficult. These individuals were generally older than the rest of the Harborview population. Few individuals experiencing developmental disabilities were admitted to HDC after the mid 1980s. The average age of those admitted after August 1986 was 49.7 years.

HARBORVIEW DEVELOPMENTAL CENTER AGE AT ADMISSION/DISCHARGE, LENGTH OF STAY

	Age at admission	Age at discharge	Years at harborview
All Harborview Residents (1964–1997)	31.4	45.4	13.7
Before Sourdough Unit (1964–1986)	19.0	38.0	19.1
After Sourdough Unit (8/86–11/97)	49.7	54.0	4.2

TRANSITION FROM HARBORVIEW TO THE COMMUNITY

Former HDC residents, families/guardians and key informants were generally positive in their views and comments about state support of the transition process from HDC to the community. While 83.3 percent of the family/guardian survey respondents said that they received adequate support during the transition of their family member, some of them reported that there were problems experienced along the way.

—Harborview provided a safe, familiar home for _____ since 1974. It was a shock to accept any change and it came on us suddenly. Probably no amount of time could have adequately prepared us.

—I was apprehensive that Harborview closing seemed to be moving rapidly in spite of public opinion. Control seemingly rested only in administrative hands.

—We had no say, was just told what would happen. We were very pleased with progress and chances to try new things.

Many families/guardians made positive comments as well.

—We noticed _____ didn't bring all his toys with him. Probably lost in HDC. Lynn George, of Assets, was the most supportive person we have ever dealt with. She was sensitive, paid attention to detail, and got things done.

—I was at Harborview for conferences over the years that the change was taking place. I also had letters and telephone conversations. They knew I wanted him to stay at Harborview as long as possible.

—There were a number of meetings at ARCA to inform parents and legal guardians of the progress of the transition.

—Harborview kept in touch with us, letting us know when and how he would be transferred to Anchorage.

—I had telephone conferences with the Harborview staff. The Anchorage staff brought my husband and I into Anchorage during the planning stages.

State agency representatives, service providers and advocates interviewed for the key informant survey also said that they thought that the state had provided adequate support (85.7 percent) to former residents and guardians during the transition process.

—I believe so. It really was a leap of faith that services would be there and be better.

—The transition went well for consumers at HDC—but Alaska has a long way to go in providing community services.

—A cynical yes, but supports set expectations that it would continue at the same level permanently. Families thought they would be getting everything they needed but this was not always the reality.

—Support was very positive from our view—families were able to choose the home. They were very happy to get all the help they did.

—Absolutely, especially during the last phase—the supports needed varies. The State did an extraordinary job of supporting people with all of their needs.

—Yes, very adequate supports. DMHDD was very supportive in reviewing needs and wants and assisting with funding.

—Our consumers had public guardians and got lots of support from DMHDD and HDC staff. They gave us information and tips, our staff was able to spend time at HDC prior to the transition. They gave us behavior management ideas for clients as well.

Former residents reported (77.8 percent) that they felt that their needs and wants were considered during the transition from HDC. At the same time, 100 percent of family and guardian respondents said that their views were considered during the transition process.

QUALITY OF LIFE IN THE COMMUNITY

One of the most frequently heard reasons for closing Harborview was that services in smaller community based programs would improve the quality of life for those living at HDC. While "quality of life" is difficult to define and often the subject of heated debate, for the purposes of this study "quality of life" includes integration into the family and community, and choice and self-determination. Former residents were asked a number of questions about their lives since they moved to community programs. Their family members/guardians were asked the same questions about their family member's life.

Former residents and their families/guardians reported that they are getting most of the services and supports they need to live in the community. However, there are a few indicators that will require continued attention by community programs. These are in the areas of choice (who you live with, what you do most days) and integration (into the neighborhood, having friends visit). It is also clear from the interviews and survey responses that community programs are working to integrate former residents into their communities (doing fun things in the community, participating in the community, transportation), this is an extremely difficult task and one with which all community programs struggle.

QUALITY OF LIFE IN THE COMMUNITY

Quality of life indicator	Response	Former residents (percent)	Family/ guardians (percent)
When goals are set for you do people	Help you reach them	95.5	80.0
Feel safe in your neighborhood?	Very safe	81.8	58.8
Do you do fun things in the community?	Yes	72.7	64.7
Are you happy with where you live?	Very happy	68.2	64.7
Do staff help you be part of your community?	Yes	68.2	66.7
Transportation if you want to go somewhere?	Most of the time	68.2	93.3
Do you get the services you need?	Yes	63.6	82.3
Do you feel lonely?	No, not often	59.1	69.2
Feel like an important part of your family?	Yes	45.5	58.3
How do your neighbors treat you?	Very good	40.9	42.9
Choice in job/what you do most days?	Yes	35.0	38.5
Do you have a job?	Yes	22.7	25.0
Choice in who you live with?	A lot	18.2	28.6
Do friends come over to visit your home?	Often	9.1	15.4

Key informants were asked if the closure had a positive or negative impact on the lives of the former residents if the facility. None of the key informants said that the impact was negative (75 percent said it was positive).

IMPACT OF TRANSFER OF HDC RESIDENTS TO COMMUNITY

	Number	Percent
Positive	12	75.0
Negative		
Both	2	12.5
Uncertain	2	12.5
N/A or No Response	1	

The key informants provided the following comments:

—Institutions like HDC are completely protected/artificial. They rob people of the richness of community and being integrated into a community. They need to be closer to the "American Dream." They are more likely to get caught up in it and make it true for themselves if they can see it. Living in the community means opportunities to work, families, volunteer in community, recreational opportunities, to be neighbors and friends with people who are not PAID to be there!

—A whole world opened to them now that hadn't before—they have more choices and freedom.

—They used to say that they will only eat certain foods—but here, they get to be involved with choosing what they eat. They are more interested and take an active part in the preparation of food and have increased appetites.

—HDC didn't feel "homey" at all—not anything like the Pioneer Home environment. It is much less restrictive here, people can do more for themselves—they are able to get own food and snacks in their own kitchen.
—Care at HDC was based on a medical model and the Pioneer Homes are based on social model approach—supporting people in what they can do in a "home like" environment. There was a very positive impact—people with dementia tend to do better in a homelike environment.
—Absolutely. You have to be there to see it. Joy, family reunification in some instances, better health, more engaged in community (having block parties—you don't get that in an institution).
—Like any decision that effects so many, there will be positive and negative effects. The changes I've seen are very positive. There is a small percentage who may do better in a different setting but its not fair to say all are doing perfectly well.

Key informants were also asked to provide examples of how a former resident's life has improved since discharge.

—A Valdez group home manager reported how much people's lives have changed, from sitting in a corner eating cookies at HDC to having their own kitchen. Now when they need a snack they can not only choose what it will be but go and get it independently. Now, these people have something to look forward to.
—One person was able for the first time to visit family members in California. A Kenai consumer had refused to move a trunk of his clothes into his room at HDC, but when he moved into a new community based home, he said, "now I can move my stuff in—because I have a room."
—Mental health consumers are more lively, socialization is more open and people are actively participating in culturally appropriate activities—like sewing fur, fishing (fish camp in summer and ice fishing in winter).
—I've had the opportunity to follow the lives of 5 people. In every case, their health is better, they are doing more, are more active and more productive in terms of functioning level. In 3 of those 5, the families are very happy with the quality of life of their family member.
—In some of the people, there was never a spark in their eyes while at HDC—now they laugh and smile!
—The majority of the people we support were at HDC at some time. Now, if someone is hungry or thirsty they can go into the kitchen and get some food and water. At HDC, they had to wait for these things to be offered first. There have been great improvements, especially with the lower functioning folks.
—Two former residents were amazed they could shut door to their bedrooms. They enjoy having privacy and a choice of churches to attend, and are doing more personal care willingly because they want to look good.

COMMUNITY SERVICES SYSTEM CAPACITY

Former residents and their families/guardians were asked to rate how well the community service system is able to provide the services and supports they need or want. While there is considerable variation between how former residents and family members/guardians rate services, both groups reported that most community services are meeting the needs of former residents well or extremely well. The service that appears to be the most problematic is employment.

More than 90 percent of the former residents interviewed said their nutritional needs were being met well to extremely well in the community. Other highly rated community services were mental health services (83.4 percent), community living services (81.8 percent) and health and medical services (77.2 percent). Education (37.5 percent) and employment (25 percent) services were the lowest rated services. This is not surprising since only 23 percent of the former residents interviewed have jobs.

Families and guardians were also asked to rate how well community services were meeting the needs of their family members. Behavioral support was the highest rated community service, with 90 percent of families and guardians saying that community services were meeting the behavioral support needs of their family members well/extremely well. Families and guardians also rated health and medical (84.6 percent), recreation/leisure (78.6 percent), nutrition (77.0 percent), community living (76.9 percent) and transportation services (71.4 percent) highly. Families and guardians reported that education services were the least likely to meet their family member's needs well/extremely well. Employment (60.0 percent), mental health services (55.5 percent), and education (37.5 percent), were less likely to be rated as meeting the needs of family members well/extremely well. More than half of the

family members/guardian survey respondents did not know if these services were being provided or chose not to answer the question on the survey.

Community services	Former residents (percent)	Family/ guardian (percent)
Nutrition	90.8	77.0
Mental Health Services	83.4	55.5
Community Living Services	81.8	76.9
Health/Medical Care	77.2	84.6
Transportation	64.3	71.4
Recreation/Leisure	60.0	78.6
Behavioral Support	54.6	90.0
Education	37.5	37.5
Employment	25.0	60.0

The majority (63.6 percent) of former residents said that they are receiving the services they need. The services and supports they need but don't have include dental/medical services, physical therapy, recreation, and environmental modifications.

Former residents and family members/guardians are in agreement that former resident's lives have improved since moving to community services. More than seventy percent of former residents (77.3 percent) reported that their lives have improved since leaving Harborview. While many family members/guardians provided positive comments about care at Harborview, they also reported that the lives of former HDC residents have improved (71.4 percent) since moving into community services.

HAS LIFE IMPROVED IN THE COMMUNITY?

Former resident's life?	Former residents (percent)	Family/ guardian (percent)
Improved	77.3	71.4
Stayed the same	18.2	21.4
Gotten worse	4.5	7.1

Comments about the change in former resident's lives from families/guardians include:

—Institutions are like a parallel universe. Life and institutions like HDC are apples and marbles. HDC was an eddy in the river of life-a stagnant eddy, a holding pattern in the flight of life.

—_____ seems happier, smiles more at Eagle House.

—The environment of a home rather that an institution has improved the quality of her life.

—She is getting good care now, but _____ and everyone was especially treated like family at Harborview.

—His needs are taken care of and he is also taken to movies and dinner or lunch every so often and he sees a doctor at Alaska Native Medical Center, he is happier.

—_____'s care providers have changed numerous times since moving to ARCA. I believe 5 to date. Of these 5, 2 related well to _____ and she was obviously well cared for healthy and happy!

—I'm putting improved because he's doing so well, but I really don't know that much about Harborview because we never went there to visit.

—More 1 on 1 attention by his care givers. More opportunities to go out on drives and out in the community.

—_____ likes his privacy and is much more relaxed in his new home situation.

—We are unable to monitor foster home for abuse potential. We could always drop in at HDC any time. Not able to discover how much "nothing" time _____ has at his home. We believe mental stimulation is important. However, his teeth are cleaned well.

THE PERMANENCE OF COMMUNITY PROGRAMS

One of the greatest fears expressed by family members as the closure of Harborivew approached was that funding of community service programs provided less permanence for their family member than a facility directly operated by the

state. In order to explore this issue, family members and guardians were asked if they thought community programs or institutions like Harborview provide greater permanence for people with developmental disabilities. Even with the closure of HDC, 54.5 percent of those responding said that they believed that institutions provided more permanence than community programs.

PERCEPTION OF PERMANENCE

	Number	Percent
Community programs	5	45.5
Institutions	6	54.5
No Response	7	

It is clear from most of the comments received that families and guardians had great confidence in the Harborview staff and the care their family members received there. Families and guardians said that the HDC staff provided a warm and caring environment. Among their comments were:

—As long as they are like Harborview. It never did have an "institutional" feeling-more like a combination of resort and large home. The small town is another reason that it was so successful. The community was so involved with Harborview, and Harborview with the community.

—I never did consider Harborview an institution, because of the excellent treatment by staff and a wonderful doctor there. Also the whole community took pride in the people staying at Harborview.

—So far I'm pleased with _____'s community program, but I believe this answer could vary according to an individual's circumstances and the verdict could still be out. Financial permanence is hopefully not at risk as well.

While the closure of HDC demonstrated that state operated institutions do not guarantee life long care, the responses from families/guardian brought forward an important issue. From the family/guardian perspective, permanence is not only a guarantee of funding, but permanence of providers. One of the positive aspects of HDC was that many of the care providers had worked there for years. HDC staff got to know HDC residents and their families on a long-term basis.

The staff at Harborview did not change often because, as state employees, their jobs offered good wages and benefit and retirement programs. Community program staff in comparable positions make significantly less, and often have minimal benefit and retirement packages. This has meant that care givers change more frequently in community programs. A number of family members/guardians commented on this.

—The staff in Harborview changed very little over the years. This is very comforting for parents and clients alike Harborview also did a terrific job of communication with us, helping with home visit arrangements, etc. They were like our extended family!

—There was greater permanence and professionalism at Harborview. I suspect there was also good cost accounting there too. Harborview provided more efficient use of state and federal facilities.

—Each person has different needs. Staff turnover frequency must be addressed. At HDC, a person's routine can continue if a staff person quits. Others (staff) know the routine. At Hope, ARCA, if the major caregiver leaves, the resident must endure discomfort and change.

ECONOMIC IMPACT OF HDC CLOSURE

Information Insights has gathered financial information on 88 percent of the former Harborview Residents who were discharged in the last ten years. We have been unable to find any financial information on the remaining 12 percent of the former Residents.

The following table details the annual costs and average annual costs of services received by the former Harborview Residents who were discharged in the last 10 years and whose current costs could be identified:

CURRENT STATUS AND SERVICE COST FOR FORMER HARBORVIEW RESIDENTS:1988–1997

[1996 Harborview Cost of Care: $164,000/person]

Status	Number	Annual cost all residents	Annual cost per resident
Deceased	[1] 18	.....	.....
Grant-Funded Services	2	$5,905	$2,953
MRDD Waiver—Funded Services	62	4,398,307	70,940
Pioneer's Homes	[1] 5	350,887	58,481
Unknown	12	?	?
Total	99	4,755,099	.....
Total Living and Known	69	4,755,099	68,914

[1] 1 Pioneer's Home resident died during fiscal year 1998; totals at end of year are 19 deceased/4 Pioneer's. Pioneer's Home costs for the remaining 4 are expected to be $299,864 per year, for an average of $74,966. This would change the average cost for all known former Harborview residents receiving services to $69,177.

In addition to the cost of services, however, other new costs are incurred by the State of Alaska for other benefits received by these former residents. Other benefits may include Food Stamps and Adult Public Assistance. Limitations in data access systems did not allow Information Insights to get an exact cost for these benefits, but based on other existing data sources we were able to develop a close approximation as follows:

Adult Public Assistance

All but two of the HDC Residents discharged in the last 10 years were adults at the time of discharge. Each would have been eligible for between $0 and $45 per month in Adult Public Assistance prior to discharge. Post-discharge, each would be eligible for $362 per month (or slightly less if receiving SSDI), for a net increase of $317 per month ($3,804 per year) in Adult Public Assistance, and a total cost for the 64 living and known former HDC residents who are not in Pioneer's Homes of $243,456.

Food Stamps

Most, if not all, of the former HDC residents are unmarried individuals, for whom receipt of Adult Public Assistance would make ineligible for more than the minimum $10 in food stamps per month. The maximum being received by the 64 living and known former HDC residents who are not living in Pioneer's Homes would therefore be $640 per month, or $7,680 per year. A summary of annualized costs, by services received, shows the following:

COST OF SERVICES AND BENEFITS FOR FORMER HARBORVIEW RESIDENTS: 1988–1997

	Grant-funded services	MRDD waiver funded services	Pioneer's homes	Total known living	Unknown [1]
Number of Individuals	2	62	4	68	12
Annual cost of services	$5,907	$4,398,307	$299,864	$4,704,078	?
Additional cost of APA (maximum)	7,608	235,848	.....	243,456	?
Additional cost of Food Stamps (maximum)	240	7,440	.....	7,680	?
Total annual cost of services and benefits	13,755	4,641,595	299,864	4,955,214	?
Average annual cost per individual	6,878	75,082	74,966	72,871	?
Total annual state cost of services and benefits	13,515	2,003,967	299,864	2,317,346	?
Average annual state cost of services and benefits	6,758	32,322	74,966	34,079	?

[1] Information Insights was not able to locate 12 of the 99 people discharged in the past 10 years from HDC.

In 1996, the Division of Mental Health and Developmental Disabilities contracted with Erickson and Associates to estimate the state cost savings from closure of Harborview Developmental Center and implementation of the Proposed Alternative Service Delivery. The Erickson study showed 1996 Harborview costs at $164,000 per resident, and estimated Alternative costs at $84,000 per resident, for a net savings of $80,000 per resident. At the time, there were 23 remaining residents of

Harborview. Two of the 23 have since died; following are the costs identified for the remaining 21:

COMPARISON OF PROJECTED AND ACTUAL COST FOR SERVICES TO FORMER HARBORVIEW RESIDENTS: 1997

	Grant-funded services	MRDD waiver-funded services	Pioneer's homes	Total known living	Unknown
Number of Individuals	.....	15	3	18	3
Annual cost of services	.....	$1,408,985	$238,698	$1,647,683	?
Additional cost of APA (maximum)	.....	57,060	.....	57,060	?
Additional cost of Food Stamps (maximum)	.....	1,800	.....	1,800	?
Total annual cost of services and benefits	.....	1,467,845	238,698	1,706,543	?
Average annual cost per individual	.....	97,856	79,566	94,808	?
Total annual state cost of services and benefits	.....	623,472	238,698	862,170	?
Average annual state cost of services and benefits	.....	41,564	79,566	47,898	?

Based on the data compiled for this study, the Erickson and Associates study was very close to the final projections. Excluding the individuals who are deceased or for whom we have no financial data, the average annual cost for the individuals discharged in 1996 and 1997 is $94,800, of which $3,270 represents benefits not considered in the Erickson study.

The Erickson and Associates study estimates, per individual, can be compared with actual costs as follows:

Study	Federal funds	GF/MH funds	Corporate receipts	GF and GF program receipts	Total costs
Erickson Study—Harborview	$57,884	$102,138	.....	$3,977	$164,000
Erickson Study—Alternatives	31,111	43,526	$3,362	6,057	84,257
Information Insights Study—Alternatives (excluding benefits not considered in the Erickson study)	46,810	44,728	.....	3,340	94,878

The alternatives have thus saved both the federal and state governments, with the bulk of the savings going to the State of Alaska. In part, the difference in allocation of savings between Federal Funds and GF/MH funds is due to the change (since the Erickson report) in Federal Medicaid reimbursement from 50 percent of costs to 59.8 percent of costs.

COMMUNITY IMPACT

The economic impact from Harborview closure is primarily on the community of Valdez, which loses the Harborview payroll and indirect impact of that payroll. At the same time, however, there is a relatively minor positive economic impact on the communities where the residents were discharged. Analysis of the distribution of community discharges shows the primary community impacts to be in Anchorage and Valdez.

Community Discharge	*Number of Individuals*
Anchorage	43
Bethel	3
Dillingham	1
Fairbanks	4
Ketchikan	3
Kodiak	2
Soldotna	2
Valdez	19
Wasilla	1
Unknown	2
[Deceased as of study date]	17

ATTACHMENT 2.—SHAWNEEN

Shawneen is a 31-year-old woman who was one of the original babies supported by Hope. She lived the first 28 years of her life in several ICFMR facilities.

On January 7, 1997, Shawneen moved into her own home with her good friend, Dana, as part of the Road Maps project. As a result of this move, Shawneen experienced remarkable physical changes. She began to sleep through the night. Her hands, which are affected by cerebral palsy, began to relax to the point that a surgery scheduled to help reduce thumb contractures was canceled. For years weight maintenance had been a challenge, but since moving into her own home she has been able to maintain her weight and has not been hospitalized once. Shawneen leads an active life, from volunteering at the Pioneer Home to enjoying the local arts. She and her house mate, along with her parents and support staff, have presented at several national conferences on how their lives have changed since moving from an ICFMR—because to them Shawneen now has a life she can truly say is her own.

ATTACHMENT 3.—ZACHARY

Zachary is a 13-year-old boy who currently lives with his father in their home community of Kenai and attends the local elementary school just like most children his age. However, Zachary's current situation could have been very different had he not received the necessary supports to live such a normal lifestyle. Zachary was born at 34 weeks gestation and suffered multiple anomalies including a coarctation of the aorta and tracheo-esophageal atresia. As a result of his multiple medical issues and dependence on medical technology, Zach spent approximately the first five years of his life in the hospital. His father was forced to quit his job and move to Anchorage to be near his son.

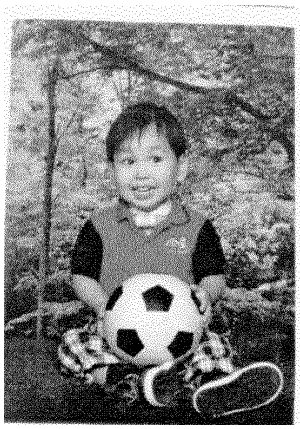
It was not until 1992 that the State of Alaska applied for a Home and Community Based Services Waiver that might allow Zach's future to be more than one of Zach's father shuttling him back and forth between the hospital and a nursing home. Zach was one of the first ventilator dependent children in the State of Alaska to be afforded the opportunity to live in a community setting. With the assistance of the State of Alaska, Zach and his family have been able to realize to the fullest extent possible their dreams for Zach—that of living a normal life. Zach receives support services in the form of in-home support, respite care, and specialized medical equipment through a Medicaid Waiver for Children with Complex Medical Conditions. Zach and his father moved back to Kenai where Zach resides with his Dad in their own home with the necessary support services for Zach to be successful. The outcome for Zach is that he is now fully integrated and thriving in a regular classroom environment at a nearby elementary school. Medically he has continued to improve and is no longer on a ventilator and does not require oxygen except during periodic illness. Zach is a happy, social kid who has many friends and is treated as a "regular" student in the classroom. He participates in all of the same activities that other kids do both in school and in the community. Zach is interested in computers, playing video games, snowmaching, and participating in any social activities with his friends and family. Through the advocacy and perseverance of those who saw Zach's abilities, not disabilities, Zach has become a successful, fully accepted member of his community.

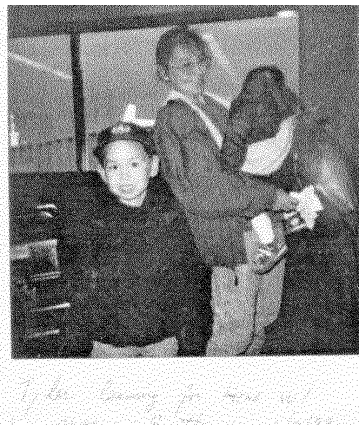
ATTACHMENT 4.—TYLER

Tyler was born on November 15, 1993. He was diagnosed at birth with a Diaphramatic Hemia, Bronchopulmonary Dysplasia, and was Developmentally Delayed. His respiratory status required insertion of a tracheotomy tube and use of CPAP to enable him to breathe. He also required gastrostomy feedings. Due to health concerns at birth, Tyler was medivaced to Anchorage and admitted to Alaska Native Medical Center.

Tyler came to Hope Community Resources in 1994 and was placed in Foster Care. From 1994 through 1999 Tyler's health continued to improve due to consistent quality home care. In 1998 and 1999 Tylor's support team worked on a plan to enable Tyler to transition to his home village of Emmonak. Tyler left for Emmonak with his mother and brother on June 7, 1999. Hope Community Resources staff have continued to monitor his progress. Tyler is doing well at this time.

Tyler's individualized costs were extensive during his hospital stay at around $65,000 in foster care and we believe minimal costs for in-home supports now (which may be delivered through Bethel Community Services).





ATTACHMENT 5.—DEVELOPMENTAL DISABILITIES DIRECT SERVICE WORKER STUDY RESULTS AND FINDINGS, GOVERNOR'S COUNCIL ON DISABILITIES AND SPECIAL EDUCATION, OCTOBER 8, 1998

EXECUTIVE SUMMARY

This study describes recruitment and retention challenges faced by 23 of the 28 Developmental Disabilities (DD) Service Providers in Alaska. The agencies in this study employed 468 direct service workers (permanent FTEs), 73 first line supervisors and 351 on-call direct service workers. Based on these findings, the number of direct service workers statewide is estimated at 570, the number of first line supervisors is estimated at 89 and the number of on-call workers is estimated at 427.

All respondents reported difficulties recruiting and retaining new workers. Approximately 17 percent of the permanent direct service worker positions were vacant at the time of the survey. This represents an estimated 98 FTE direct service worker vacancies statewide. On an annual basis, 948 direct service positions have to be filled to replace workers who have left. An additional 114 new workers have to be hired to provide direct services to the estimated 458 new people with developmental disabilities who begin receiving services each year statewide (duplicated count).

Recruitment and retention costs are large and growing. Respondents reported spending $28,112 in advertising to recruit new workers in the first half of fiscal year 1998. This translates into estimated annual advertising costs of approximately $68,446 across the 28 agencies statewide. Survey respondents paid 34,683 hours of overtime during this same time period to cover shift vacancies due to unfilled positions. This translates into an estimated 84,446 hours annually, statewide and an estimated statewide annualized cost of $724,542 in overtime expenditures (beyond the straight time expenses). Survey respondents spent $131,170 for other recruitment costs (e.g., fingerprinting, administrative time, Hepatitis B vaccinations) April 16-June 12, 1998. This translates into an estimated statewide-annualized cost of $956,532 in other recruitment costs.

Direct service worker positions were vacant for an average of four weeks before being filled. When positions were advertised, the average agency received eight applications. However, the number of applicants who were actually qualified was only 50 percent. These findings suggest there is a need for a targeted, systemic workforce development plan to address challenges facing the DD service delivery system.

A majority of respondents reported a number of major problems, which included: finding qualified direct service workers (82 percent); wage and hour considerations (70 percent); direct service worker turnover (68 percent); and staff training and development (65 percent). The top three recruitment barriers or disincentives reported were compensation and pay (81 percent), hours of work (76 percent) and lack of qualified applicants (70 percent).

These findings indicate recruitment and retention challenges are pressing issues that must be addressed in order to ensure the maintenance of safe, quality services in the community for Alaskans with developmental disabilities. The Governor's Council on Disabilities and Special Education made several general recommendations about ways to address these challenges. These recommendations include strat-

egies related to comparable wages and benefits, recruitment, retention, education and training, and efficiency and productivity.

These strategies provide a starting point for addressing the workforce development challenges faced by DD Service Providers. The development, implementation and evaluation of an effective workforce development program in Alaska will require the cooperation and collaboration of a variety of stakeholders, including State agencies, provider agencies, consumer and parent advocacy organizations, the legislature, the Alaska Mental Health Trust Authority and postsecondary educational institutions.

BACKGROUND INFORMATION

Direct Service Workers are employees of agencies serving individuals with developmental disabilities. Their primary job responsibilities are to provide training, support, supervision and personal assistance to these individuals. At least 50 percent of their work is spent in direct care tasks. Direct service workers may do some supervisory tasks, but their primary job responsibility is direct service work. Some direct service workers are hired as on-call workers. An on-call worker is any worker who is not guaranteed a certain number of hours per week or month.

Direct service workers assist individuals with developmental disabilities to lead self-directed lives and actively participate in and contribute to community life. They have a variety of titles and positions such as residential counselor, respite worker, job coach, paraprofessional and direct care staff. They work in a variety of community settings including residential group homes, individual and family homes, work sites and parks and recreation settings. Some may work in more than one setting. Direct service workers work with people with developmental disabilities of all ages who have varying abilities and needs.

The number of individuals and families who receive community-based services has increased considerably since 1992. In addition to new legislative increments, there are a number of factors contributing to this growth. The Home and Community-Based Waiver program was implemented in 1994. Harborview Developmental Center was closed in December 1997. And finally, core services were implemented in fiscal year 1998. In fiscal year 1999, as a result of legislative funding increases, Medicaid refinancing and core services, it is anticipated that every person on the Developmental Disabilities wait list as of 6/30/98 will receive at least some services by 6/30/99.

However, growth can create problems. If the question is asked, "Is the community prepared to handle this growth?" the answer is "No, not any longer!" In Alaska, additional revenues have been allocated towards serving new people from the wait list. No increases have been allocated for the basic provider infrastructure in many years. As a result, the cost of inflation has hit providers hard. Staff turnover is high and it is difficult to recruit qualified applicants, affecting the quality of care provided to Alaskans with developmental disabilities and their families. As services have become more community- based and decentralized, the demand for direct service workers has increased, training needs have changed and turnover rates have increased.

Previous studies indicate that recruitment and retention challenges experienced by agencies supporting people with developmental disabilities are substantial. One federally funded study followed 175 newly hired direct service workers in 139 small Minnesota group homes to determine turnover rates (Larson, 1996 cited in Larson, 1997). Turnover rates among direct service workers in this study averaged 47 percent per year in 1994 and 50 percent per year in 1995. Even worse, 41 percent had left before completing six months on the job and another 25 percent left before finishing 12 months on the job. On an annual basis almost 50 percent of these position turn over. These statistics parallel those experienced by Alaska DD service providers.

While few studies have focused on the factors associated with successful recruitment, "a lot of research has identified factors associated with turnover including:

—staff characteristics (older staff are less likely to leave, women are less likely to leave),

—pay and benefits (higher paid workers are less likely to leave, those with health insurance are less likely to leave, and those with paid leave time are less likely to leave),

—work attitudes (those whose pre-hire expectations are met, who are satisfied with their jobs, who are committed to the organization are less likely to leave),

—employment context (turnover is higher when unemployment is lower) and

—agency characteristics (turnover is higher in smaller agencies, in newer agencies and newer settings, and in agencies serving people with more severe disabilities)"—(Larson, Hewitt & Lakin, 1994 in Larson 1997, p.4)

This study examines salary, recruitment and retention issues in an effort to identify solutions that might be helpful in addressing these challenges as well as training and staff development issues.

METHODS

Recognizing the magnitude of salary, recruitment and retention issues, the Governor's Council on Disabilities and Special Education, in collaboration with the Association on Developmental Disabilities (a trade association of Developmental Disabilities (DD) service providers), conducted a statewide survey in April 1998. All 28 of the DD service providers were surveyed in an effort to quantify the extent and type of challenges confronting the DD service delivery system. The survey focused on both permanent and on-call direct service worker positions.

The following definitions were used for this study:

Direct Service Workers (DSW).—People whose primary job responsibilities are to provide training, support, supervision and personal assistance to individuals with developmental disabilities. At least 50 percent of their work are spent in direct care tasks. Direct service workers may do some supervisory tasks, but their primary job responsibility and more than 50 percent of their hours are spent doing direct service work.

Full Time Equivalency (FTE).—Number of people who work the standard workweek of 40 hours (e.g., two workers who each work 20 hours per week equal 1.0 FTE).

On-call Worker.—Any worker who is not guaranteed a certain number of hours per week or month.

The study was conducted between April 16, 1998 and June 12, 1998. Surveys were mailed to the Executive Director of each agency. At least one telephone call was made to contact non-responding agencies in late May and early June. Of the 28 agencies surveyed, 23 returned surveys for an overall response rate of 82.1 percent. Follow-up calls were made to all agencies whose returned surveys were unclear.

The Council used the Occupational Employment Statistics (OES) to compare the average and median hourly wages of DD direct service workers with similar positions in the community. The Alaska Department of Labor collects OES wage data as a part of a State-federal cooperative program. The data include both private and public (government) employers. The OES wage data was weighted according to the number of positions in each comparable occupation. DD service provider wage data was also weighted according to the number of direct service workers each agency employed.

SURVEY FINDINGS

Agency characteristics

The 23 agency respondents supported 3,000+ people with developmental disabilities (duplicated count) to live and participate in local communities with 468 FTEs employed as direct service workers, 73 front line supervisors and 114 support staff and administrators. They also employed 351 on-call direct service workers, 3 on-call front line supervisors and 24 on-call support staff and administrators (see Table 1). The average ratio of direct service workers to the individuals supported in the community, excluding on-call workers, is 1 to 6 and the median ratio is 1 to 7. If on-call workers are included, both the average and median ratios are 1 to 4.

The 23 agencies opened 13 new sites or services in the past 12 months and expanded the number of sites or services by 18. A total of 376 new consumers were supported. If the ratio of direct service workers to individuals supported is consistent from year to year, approximately 94 new direct service workers, including on-call workers, were added to these agencies during the same time period.

TABLE 1.—CHARACTERISTICS OF SURVEY RESPONDENTS

	Total	Average	Median
Number of People Served (duplicated count)	3,007	131	58
Number of New Persons Served in the Past Year	376	16	7
Number of Direct Service Workers (FTEs)	468	21	8
Number of Front Line Supervisors (also have direct service responsibilities)	73	3	1
Number of Support Staff/Administrators	114	5	.75
Number of "On Call" Direct Service Workers	351	15	5

TABLE 1.—CHARACTERISTICS OF SURVEY RESPONDENTS—Continued

	Total	Average	Median
Number of "On Call" Front Line Supervisors	3	.13	[1] NA
Number of "On Call" Support Staff/Administrators	24	1	[1] NA
Number of New DD Sites/Services	13	.56	[1] NA
Number of Expanded DD Sites/Services	18	.78	[1] NA

[1] The median is less than 1 in all of these instances.

A variety of services were provided by the 23 agencies at the time they responded to the survey (see Table 2).

Services included care coordination or case management (91 percent), respite (83 percent), in-home support (74 percent), vocational (70 percent), supported living (65 percent), foster care (61 percent), shared care (52 percent), personal assistance services (48 percent), group home (30 percent), and sexual offender treatment (22 percent). Nine other services were also provided by these agencies. The vast majority of respondents provided two or more types of services.

1,197 people received care coordination or case management services. However, this number is somewhat misleading because some people only receive care coordination or case management services, while others receive them as a part of other services, (e.g., vocational support). Following care coordination or case management, the number of people with developmental disabilities and their families supported with the following services was: respite (714 people), vocational support (394 people), supported living (277 people), personal assistance services (234 people), in-home support (188 people), group home (126 people), foster care (119 people), shared care (27 people) and sexual offender treatment (22 people).

TABLE 2.—TYPE OF SERVICES PROVIDED AND NUMBERS SERVED

Service	Number of providers	Total served	Average	Median
Case Coordination	21	1,197	57	26
Foster Care	14	119	9	3
Group Home	7	126	18	5
In-Home Support	17	188	11	3
Personal Assistance Services	11	234	21	2
Respite	19	714	38	34
Shared Care	12	27	2	1
Supported Living	15	277	19	12
Sexual Offender Treatment	5	22	4	5
Vocational Support	16	394	25	12
Other	9	[1] 1,197	133	49

[1] 20 day habilitation, 40 core services, 49 one-time funding, 84 legal advocacy services, 691 Information and Referral, 175 Family Resource Project training, 138 family support.

Staffing challenges

Of the 23 DD service providers, 82 percent reported that finding qualified direct service workers was a major problem (see Table 3). Other major problems included wage and hour considerations, staff training and development, and direct service worker turnover.

Staff motivation was a problem for only 23 percent of the respondents, although it cut across both urban and rural agencies.

TABLE 3.—*Major Staffing Problems*

	Percent of respondents
Finding Qualified Direct Service Workers	82
Wage and Hour Considerations	70
Direct Service Worker Turnover	68
Staff Training and Development	65
Staff Motivation	23

Recruitment barriers

Respondents identified the extent to which several factors were barriers or disincentives to their recruitment efforts. Overall the top five barriers were: compensation or pay (81 percent), hours of work (76 percent), lack of qualified applicants (70 percent), lack of applicants (62 percent) and workload (55 percent) (see Table 4). At

least 25 percent of the respondents reported that each of the other listed barriers caused moderate or severe recruitment challenges for their agency. Clearly, recruitment was a significant issue for DD providers with the rate of pay and compensation, hours of work and the lack of qualified applicants considered major contributors to the problem.

TABLE 4.—PERCENT OF AGENCIES REPORTING RECRUITMENT BARRIERS

Recruitment barrier	Degree of difficulty (percent)			
	None	Mild	Moderate	Severe
Compensation/Pay		19	24	57
Hours of Work (nights, weekends, holidays)	19	5	62	14
Lack of Qualified Applicants	9	22	35	35
Lack of Applicants	5	33	38	24
Workload (amount or difficulty of work)	18	27	41	14
Severity of Consumers' Disabilities	24	24	38	14
Lack of Recruitment Resources	30	25	30	15
Lack of Child Care	32	32	32	5
Applicants Don't Have Work Ethic	33	33	29	5
Location (transportation, commute)	33	38	14	14

Extent and Cost of Recruitment Challenges

At the time of this survey, respondents reported 130 (80.5 FTEs) direct service worker vacancies (see Table 5). This was 17 percent of the full-time permanent direct service workforce or 28 percent of the total workforce. Direct service worker positions were vacant for an average of four weeks, ranging between 0 and 12 weeks.

When direct worker positions were advertised, the average agency received eight applications (ranging two to 20). However, the number of applicants who were actually qualified for the job for which they were applying was only 50 percent. When qualified applicants were found, they often didn't accept the job once wages and benefits are discussed.

The agencies surveyed spent $28,112 for advertising in the first six months of fiscal year 1998 ($60.07 per direct support worker position, excluding on-call positions) (see Table 6). The agencies also paid 34,683 hours of unplanned overtime due to staff vacancies during that same time period (74.1 hours per direct service worker). The cost of unplanned, vacancy overtime is approximately $595,160 per year for these 23 agencies or $1,272 per direct service worker.

In addition to advertising and overtime costs, the DD providers had a number of other recruitment costs, including administrative time, the hiring process itself, fingerprinting, TB tests, Hepatitis B vaccinations, orientation training and other necessary training (e.g., First Aid, CPR and Mandt training). These expenses equated to an average statewide cost per hire of $1,009 (see Table 7). Total average statewide cost per hire was $2,341.

TABLE 5.—STAFF VACANCY CHARACTERISTICS

	DSW	"On-Call" DSW
Number of Staff Positions	468	351
Total Number of Vacancies	[1] 130	[2] 24
Total Number of Vacant FTEs	80.5	[2] 24
Percent of FTEs that were Vacant when Survey was Completed	17	7
Total Number of Applicants for Last Position	166	NA
Total Number of Qualified Applicants	83	NA
Percent Qualified	50	NA
Average Number of Applicants for Last Position	8	NA
Average Number of Qualified Applicants	4	NA
Percent Qualified	50	NA
Average Number of Weeks Position was Vacant	4	NA

[1] 31 Full Time and 99 Part Time positions.
[2] One respondent indicated that the agency "hires as many qualified applicants as we can."

TABLE 6.—*Recruitment Expenses*

	Responses
Total Spent on Advertising (7/1/97–12/31/97)	$28,112.00

TABLE 6.—*Recruitment Expenses—Continued*

	Responses
Amount Spent on Advertising Per Direct Service Worker—All Employees [1]	[1] 34.32
Amount Spent on Advertising, Excluding "On-Call" Workers	60.07
Total Number of Overtime Hours (7/1/97–12/31/97)	34,683

[1] Includes costs for both the 468 Full Time Employees and the 351 "On-Call" Workers.

TABLE 7.—*Cost Per Hire*

Expense	*Average cost*
Advertising	$60
Overtime	1,272
Other Recruitment Costs	1,009
Total	2,341

The cost to fill the 130 positions that were vacant between April 16 and June 12, 1998 was approximately $304,330. According to both Alaskan and national experience, 41 percent (53) of these positions will be vacant again in less than six months and another 25 percent (33) will be vacant within a year.

Estimated Statewide Challenge for DD Service Providers

One primary purpose of this study was to develop statewide estimates of the number of staff members and the extent of recruitment challenges among DD service providers. This study included 82 percent of all Alaska DD service providers. The results of this study suggest that the total number of direct service workers statewide is approximately 570 (see Table 8). The number of front line supervisors is estimated to be 89 and the number of support staff and administrators 139. The number of on-call workers is estimated at 427.

In the two-month period from April 16 to June 12, 1998, 158 direct service worker positions were estimated to be vacant statewide (79 positions per month). This equates to a 166 percent turnover. Given the projected statewide increase of 458 new people served by these agencies in 12 months and the overall ratio of direct service workers to people supported, an additional 114 direct service workers need to be hired. Therefore, assuming these numbers remain constant (79 vacancies per month and 9.5 new workers hired per month), 1,062 direct service worker positions are projected to be refilled or filled annually.

Statewide estimates of annual recruitment expenses to maintain a workforce of 570 permanent workers with a 166 percent turnover rate include: $68,446 for advertising; $724,542 for overtime (counting only the overtime portion of the costs for a worker earning an average of $10.38 per hour plus payroll expenses and benefits); and $956,532 for Other Recruitment Costs for a total of $1,749,520. The cost of recruitment and hire of the 114 staff position added to the workforce are estimated to be $121,866.

TABLE 8.—STATEWIDE ESTIMATES FOR DD SERVICES PROVIDERS

	Study total	Statewide estimate
Number of Agencies	23	28
Number of People Served (duplicate number)	3,007	3,661
Number of Direct Service Workers	468	570
Number of First Line Supervisors (also have direct service responsibilities)	73	89
Number of Support Staff and Administrators	114	139
Number of On-Call Workers	351	427
Total DSW workforce vacancies (full-time and part-time) 4/16–6/12/98 [1]	130	158
Total annual DSW workforce (full-time and part-time) vacancies	780	948
Total Spent on Advertising 7/1/97–12/31/97	$28,112	$34,223
Total Spent on Advertising in 12 Months	$56,224	$68,446
Total Hours of DSW Overtime 7/1/97–12/31/97	34,683	42,223
Total Hours of DSW Overtime in 12 Months	69,366	84,446
Total Cost of Overtime @ $8.58 (overtime portion of time and one-half costs and payroll expenses 7/1/97–12/31/97	$297,580	$362,271
Total Spent on DSW Overtime in 12 months	$595,160	$724,542
Total Other Recruitment Costs 4/16–6/12/98	$131,170	$159,422
Total Other Recruitment Costs in 12 months	$787,020	$956,532
Number of New People Supported in 12 Months	376	458

TABLE 8.—STATEWIDE ESTIMATES FOR DD SERVICES PROVIDERS—Continued

	Study total	Statewide estimate
Number of New Direct Service Workers Needed	94	114

[1] 29 Full Time and 99 Part Time Positions

Strategies currently used to address recruitment and retention issues

Recruitment and retention issues were significant problems for DD service providers. Although this study was not intended to provide a comprehensive analysis of solutions to these challenges, the survey did ask respondents to indicate which, if any, of 12 possible strategies they used in recruitment and retention efforts (see Table 9). Overall, the most frequently used strategies were to provide flexible hours (e.g., flextime, job sharing, part-time work), allow time off without pay, offer paid leave time, provide competitive benefits and provide competitive wages. While many administrators reported using these strategies, they also reported struggling with recruitment and retention challenges.

Respondents reported that wages and benefits were competitive among DD service providers. However, they also reported that wages and benefits were not competitive with other private and public (government) positions. Funding limits prevented agencies from offering retirement, and merit, step and cost of living increases as incentives. When positions with higher wages and better benefits become available in other agencies, staff moved on to those positions.

Some agencies were able to offer more innovative strategies such as enhanced job responsibilities, education support and peer mentoring opportunities.

Although 50 percent were able to offer bonuses for starting or completing a certain number of months on the job, they lowered the starting wage to offer the bonus after six months or one year of employment. It was reported that the lowered starting wages negatively impacted recruitment efforts.

Only two agencies offered bonuses to current employees who recruited new workers or provided agency vehicles for staff use. No agencies provided childcare. Respondents also mentioned using internships as a way to find qualified staff, conducting extensive matching of staff and consumer lifestyles to make employment a natural of the employee's regular life and allowing independence as to how staff and consumers meet the goals of the service plan. The relative effectiveness of these various strategies in attracting and retaining good employees remains untested within the broader DD service provider community.

TABLE 9.—*Recruitment and Retention Incentives Used by DD Providers*

Incentives	*Percent of respondents*
Flexible Hours (flex time, job sharing, part-time work)	91
Allow Time Off without Pay	87
Provide Paid Leave Time	78
Competitive Benefits	65
Competitive Wages	57
Bonuses/Raises for Starting or Completing a Certain Number of Months on the Job	48
Enhanced Job Responsibilities	48
Education Support (tuition reimbursement, time off)	43
Peer Mentoring Opportunities	39
Bonuses to Current Employees for Recruiting Staff who Stay	9
Transportation for Employees (agency-owned vehicle for employee use)	9
Provide Child Care	

The three most common benefits provided to direct service workers included mileage reimbursement, personal or vacation leave and medical insurance (see Table 10). At least 50 percent of the DD service providers offered sick leave, dental insurance, life insurance, retirement benefits and disability insurance. Less than 50 percent offered vision insurance, annuity plans and educational benefits. Respondents also mentioned providing a cafeteria plan for employees, which allowed employees to choose where to put their benefits (e.g., medical annuity plan). The relative effectiveness of these various benefits is unknown.

Some agencies provide benefits only to full-time staff. Other agencies indicated they considered hourly workers to be temporary employees and, provided no benefits. These positions turned over very frequently. Also, with few exceptions, hourly workers were not guaranteed hours.

TABLE 10.—*Benefits Offered by DD Providers*

Incentives	*Percent of respondents*
Mileage Reimbursement	83
Personal or Vacation Leave	83
Medical Insurance	83
Sick Leave	70
Dental Insurance	70
Life Insurance	65
Retirement Benefits	61
Disability Insurance	48
Educational Benefits	43
Vision Insurance	39
Annuity Plan	39

Other findings

Twelve respondents elaborated on the recruitment and retention issues they faced in the Comments Section of the survey. Primary areas of concern centered on the inability to attract and retain qualified employees due to wage and budget restrictions. Wage rates and benefit packages were not competitive with other private and public (government) positions. Services had increased, but funding for such budget items as additional staff, travel and adequate office space had not.

Agencies reported that many of these problems were interrelated. For example, low wages contributed to staff turnover and the inability to attract good qualified workers, as did the level of benefits agencies were able to offer. If agencies were able to offer raises to staff, it was at the expense of having adequate office space, clerical support, bookkeeping, program equipment, etc.

PARITY STUDY

Alaska Department of Labor (DOL) information was used to prepare a market analysis, including a projection of job demand and comparable wages. DOL materials indicated continued growth and competition for staff should be expected until 2005. The service industry is the fastest growing segment of the job market. DOL data was also used to compare wages paid for similar jobs.

DD Service Providers must compete for employees in a segment of the labor market composed of largely unskilled workers, despite the level of skill needed and the responsibility assigned to direct service workers. The average wage paid to DD Respite and Residential Workers was $9.14 per hour. Table 11 shows the other occupations seeking employees in the same segment of the labor market.

TABLE 11.—OTHER OCCUPATIONS SEEKING EMPLOYEES IN SAME LABOR MARKET SEGMENT

Occupation	Average wage	Amount more than DSW wage
Messenger or Delivery Persons	$10.52	$1.38
Janitors/Cleaners Ex Maids/House Cleaners	9.79	.65
Laborers, Landscaping and Groundskeeping	10.82	1.68
Order Clerks	11.47	2.33
Freight, Stock & Materials Movers: Hand	11.98	2.84
Hand Packers and Packagers	11.17	2.03
Sales Agents (Retail)	9.54	.40
Stock Clerks (Sales Floor)	9.42	.28
Telemarketers/Door-to-Door Sales Workers	9.80	.38

A parity wage for direct service workers was developed as follows:

—Twelve occupations were selected from the Occupational Employment Statistics (OES) maintained by DOL. These occupations focus on residential support, care coordination, supervision, medical support and technology, teaching, counseling and vocational education. The emphasis varies across occupations but that is also true across the range of DD service providers.

—The average hourly and median wages cited in the OES were used for comparison and calculation.

—A "weighted average" was used rather than a "simple average" to increase statistical validity. There was a large difference in the number of job orders (i.e. the market demand) among these occupations. DD service provider wage data was also weighted according to the number of direct service workers each agency employed.

The difference in average hourly wages paid to all DD direct service workers was $3.54 per hour (see Table 12). Respite and Residential Workers were generally paid less than other direct service workers were. As can be seen in Table 13, the difference in average hourly wages paid to Respite and Residential Workers was $4.78 per hour.

TABLE 12.—COMPARABLE OCCUPATIONS—HUMAN SERVICE WORKERS

Occupation	Average hourly wage	Median hourly wage
Residential Counselors	$10.36	$10.63
Human Service Workers	14.10	12.91
Vocational/Educational Counselors	21.86	20.58
Physical Therapy Aides	15.17	11.50
Recreation Workers	9.74	9.85
All Other Professional, Technical and Paraprofessional	17.97	16.92
All Other Therapists	15.74	12.93
Nursing Aides, Orderlies and Attendants	12.47	11.92
Medical Assistants	12.34	11.95
All Other Health Service Workers	13.13	12.70
All Other Service Workers	10.97	10.43
All Other Health, Professionals, Technicians, Paraprofessionals	17.70	15.34
Average	13.51	12.43
Weighted According to the Number of Positions	13.92	14.00
DD Direct Service Workers	[1] 10.38	[2] 10.53
Difference	3.54	3.47

[1] Weighted Average.
[2] Weighted Median.

TABLE 13.—WAGES PAID TO RESPITE AND RESIDENTIAL WORKERS

Occupation	Average hourly wage	Median hourly wage
Weighted Comparable Human Service Workers	$13.92	$14.00
Respite and Residential Workers	[1] 9.14	[2] 9.48
Difference	4.78	4.52

[1] Weighted Average.
[2] Weighted Median.

The average wage of $13.92 for comparable human service workers represents an increase of $4.78 per hour for on-call respite and residential staff and an increase of $3.54 for permanent direct service workers. To obtain wage parity for all DD agency direct service workers would cost $6,238,084 (see Table 14).

TABLE 14.—*Amount of Money Needed to Raise DSW Wages to that of Comparable Occupations*

Calculation	*Amount needed*
427 On-Call Respite/Residential Workers × $4.78 × 1,000 hrs	$2,041,060
570 Permanent DSW × $3.54 × 2,080 hrs.	4,197,024
Grand total	6,238,084

DISCUSSION AND RECOMMENDATIONS

Despite the obvious cost issues of wage parity, it is an issue that must be addressed. The consequences for approximately 2,000+ Alaskans and their families who are dependent upon these staff for their care should not and cannot be ignored. Staff turnover creates instability and emergency situations that require frequent, intensive interventions. The cost to respond is far more costly than an across the board increase in wages and benefits.

Qualified, well-trained and satisfied direct service workers are the backbone of the DD service delivery system. They are the reason why individuals with developmental disabilities remain safe, happy and productive community settings. The longevity of DD staff is critical to their successful, stable participation in the community.

DD Service Providers are no longer in a position to increase wages and benefits or provide other incentives at the expense of their basic administrative infrastruc-

ture. Any increase in wages and benefits means a reduction in the number of hours of support provided to Alaskans with developmental disabilities. Recognition and positive reinforcement can only go so far.

The DD service delivery system has created additional complications. Although the DD service providers are committed to individualized, consumer- centered services, it is difficult to attract and retain qualified staff, given their inability to guarantee hours and frequency schedule changes. Costs far exceed the allowable Medicaid Waiver limits for services such as care coordination and assisted living.

Training and recordkeeping expectations have increased without a concurrent increase in funding. Because services are individualized, small agencies often need to hire part-time workers to remain flexible for individuals and families. The inability to offer full-time work makes it difficult to attract qualified applicants. In addition, it is sometimes difficult to hire staff to meet consumers' unique needs (e.g., staff fluent in Yupik).

"Research and best practices examples have identified several types of interventions that might help agencies to address their recruitment and retention challenges. These interventions range from providing realistic industry previews to high school and vocational college students before they enter the workforce, to improving access to preferred benefits and paid leave for part time workers, to instituting specific recruitment incentive programs, to developing welfare to work programs to train and match workers who want and need to work with vacancies in human service agencies. The challenge is to find ways to share these potential solutions with agencies statewide, to test their relative effectiveness, and to implement on a broad scale the most effective interventions to address recruitment and retention challenges."—(Larson, 1997, pp. 18–19)

In order to respond to the pressing workforce development issues identified in this study, Alaska must develop an effective workforce development program. Whatever workforce development program is developed, it must assist in planning and maintaining safe, quality community services for all infants and toddlers with disabilities. It must be comprehensive and available to all ILP Providers in Alaska. It must identify, develop and support specific strategies to address low wages, labor shortages, a lack of qualified applicants and high turnover rates. It will require the cooperation and collaboration of a variety of stakeholders including State agencies, provider agencies, consumer and parent advocacy organizations, the legislature, the Alaska Mental Health Trust Authority and postsecondary educational institutions.

The Governor's Council on Disabilities and Special Education offers the following general recommendations for review and action by key stakeholders:

COMPARABLE WAGES AND BENEFITS STRATEGIES

Place particular emphasis on increasing the wages of respite and residential workers since these positions have the highest turnover.

Contact other states (e.g., Oregon) that have been successful in receiving wage and/or benefits increases for DD direct service workers to learn more about their strategies and applicability to Alaska.

Decide how to best present the information in this study to members of the legislature.

Develop a comprehensive legislative strategy presented in "bottom line" business terms as well as human services terms.

RECRUITMENT STRATEGIES

Expand the pool of Direct Service Workers through the Alaska School-to-Work, Welfare-to-Work, Return-to-Work and Displaced Worker programs.

Target recruitment, training and support programs to persons in specific age, disability and culture groups.

Improve DSW compensation, benefits, benefits flexibility and alternative compensation strategies (e.g., tuition benefits and raises upon completion of degree programs).

Develop a better understanding of DSW roles and characteristics and the needs of people filling those roles.

Consider making the position of recruiter a step in agencies' career ladder.

Share innovative recruitment strategies with other DD Service Providers.

Stress the availability of mentors and peer support during interviews.

RETENTION STRATEGIES

Develop realistic job previews.

Provide training and technical assistance to measure and reduce staff turnover.

Develop a program to enhance the status of Direct Service Workers.

Share innovative retention strategies with other DD Service Providers
Establish mentor and peer support programs.
Implement a peer assistance program between consumers to allow for staff networking.

EDUCATION AND TRAINING STRATEGIES

Identify DSW training needs.
Identify DD Service provider training needs.
Develop an "Earn as You Learn" program (competency-based training, multi-level degree options).
Examine the cost and programmatic implications of training people for universal worker positions across a variety of employment settings.
Provide technical assistance, training and support on the delivery of training by mentors and supervisors.
Expand training and career development opportunities for Direct Service Workers.
Develop a competency-based training program for DSW mentors and supervisors.

EFFICIENCY AND PRODUCTIVITY STRATEGIES

Implement the Medicaid Waivers Study.
Examine the DD service delivery system in terms of the wait list for services, the use of one-time funds and the allocation of resources across communities.
Examine the cost implications of improving recruitment and retention outcomes.
Promote consumer-directed services.
Examine the cost and programmatic implications of joint purchasing programs for insurance, materials, supplies, equipment; cooperative childcare programs, etc., perhaps in collaboration with the United Way and other non-profit trade associations.
Consider establishing a cooperative network to coordinate recruitment efforts across all DD service providers in the state (e.g., participation in job fairs, 1–800 number, videotapes, brochures, sales portfolios, Internet).
These strategies provide a starting point for addressing the workforce development challenges faced by DD Service Providers. This study identified significant needs in this area. These needs must be addressed if Alaska is to continue providing safe, quality services in the community for individuals with developmental disabilities.

Senator STEVENS. Thank you. Mr. Jessee.

STATEMENT OF JEFF JESSEE, ALASKA MENTAL HEALTH TRUST AUTHORITY

Mr. JESSEE. Thank you, Senator Stevens. For the record, my name is Jeff Jessee, and I am from the Mental Health Trust Authority, a unique public foundation which uses the income from its endowment managed by the Permanent Fund Corporation and 1 million acres of land across Alaska to improve the lives of our beneficiaries, which include people who experience mental retardation and other mental disabilities.

As the commissioner has said, Alaska has much to be proud of, but we have far to go. In many ways, our Special Olympians are not that special at all. In fact, in many important ways they are not. They want and need many of the things and all the things that we all want and need, housing, employment, health care, and a place in our community.

The commissioner talked about our efforts to deinstitutionalize people in Alaska. The important thing to know is that we did it the right way, not by simply turning people out onto the streets, but by developing the community-based alternatives that they need to live without institutions.

Through our partners, such as the Alaska Housing Finance Corporation, an organization that has supported the development of these housing alternatives for many years, we were able to provide these kinds of alternatives.

It is important also to realize that 70 percent of all of these community programs are paid for through the medicaid program, one of the most essential programs for our beneficiaries.

In rural Alaska, we face special challenges to help people live in their communities, cared for by their families and communities. We need to increase the availability of supported housing and assisted living facilities in rural communities. Not only will this provide services in their homes for our Special Olympians and others, but it will provide badly needed cash economy jobs in those communities, a situation I know you are well aware of.

In the area of employment, nothing is a bigger barrier to employment than the lack of affordable health care coverage. As the commissioner stated, that is often the major barrier to people becoming employed. In my work at the Disability Law Center, I had to recommend that my clients not take jobs because they would lose their medicaid eligibility, and the kind of jobs they could get would not come with health care coverage.

We need more employers like this hotel, the Sheraton, Burger King, Carr's, McDonald's. We all know that the pride and joy that we see on the faces of our Olympians as they compete successfully in the Games, but I have seen the smiles and the pride and the joy of getting that check for a real job well done.

In the area of health care, as the commissioner said, the Infant Learning Program is really the starting point of maximizing the potential of all people who experience mental disabilities. As she also mentioned, the special smile effort on the part of the Special Olympics identified one-third of the athletes that came through as in need of pain or infection management for their dental problems. It makes simply no sense to just wait for dental problems to get to that level before any care is offered.

Your efforts to support us and the State with FAS prevention programs is absolutely one of the most important things that is happening. As many people have said, it is the number 1 most preventable cause of mental retardation that we know about.

In rural Alaska, to address these issues we also need a network of behavioral health aids, patterned after our very successful health aid model which you, Senator Stevens, helped pioneer in the State. This would allow the addressing of the underlying issues of alcohol abuse, mental health problems, and the special support needs of our individuals that are trying desperately to live in their home communities with their families.

They also need a place in the community. They need support often to live in the community independently, but what does it say when the wages of people that we pay to provide the support is less than a beginning clerk at a Wal-Mart? We need additional workforce development. We need better training for our people who are in these communities, and we need a recognition that people who experience mental disabilities can have a full and complete participation in our community.

It used to be that we sterilized people with mental disabilities. Now, those people have families, and they need help to support those families, and the Mental Health Trust, among others, is putting out grant money for supporting parenting programs to assist them in becoming better parents.

They have problems with the law, which is why the Trust and others have supported the development of the mental health courts. Senate bill 1865 passed the Congress last year, but was not funded. We need your help with that.

PREPARED STATEMENT

Finally, I want to stress the importance of the Developmental Disabilities Act. The DD Act provides a tripod of effort that has become the backbone of Alaska's efforts in this regard, the Developmental Disabilities Planning Council, the university-affiliated program, and the Protection Advocacy Agency.

Thank you, Senator, for your attention, and thank you for coming.

[The statement follows:]

PREPARED STATEMENT OF JEFF JESSEE

Mr. Chairman and members of the Committee on Appropriations, thank you for the opportunity to testify today at a special hearing on promoting health for persons with Mental Retardation.

I represent the Alaska Mental Health Trust Authority, a public foundation that serves four groups of beneficiaries: people with mental retardation and similar disabilities, people with mental illness, chronic alcoholics with psychosis, and people with dementia. Our mission is to improve the lives and circumstances of Trust beneficiaries. The Trust is concerned with the whole person: health, safety, economic productivity, housing, and living with dignity in the community. I have attached some background information about the Trust to these comments.

The Trust is pleased to have this opportunity to address the Committee during the 2001 World Games held here in Anchorage, Alaska. In 1999, Anchorage hosted the International People First conference, with thousands of visitors with mental retardation and similar disabilities from countries around the world. The People First Conference and now the World Games helped pave the way for Anchorage to be as accessible to people with disabilities as it is today.

The Special Olympics report on health care brought forward many issues that ring true for Alaskans with mental retardation and similar disabilities. The Trust, as a foundation that serves the same people as does the Special Olympics, has identified several similar issues and has partnered with the State of Alaska on many levels to improve the health and overall lives of the 11,000 Alaskans with developmental disabilities. Our written comments address some of these below.

For further information, pleas contact me a 550 West Seventh Avenue, suite 1820, Anchorage, Alaska 99501 or phone (907) 269–7960. You may also find it helpful to contact the Governor's Council on Disabilities & Special Education, the Disability Law Center, or the Center for Human Development, Alaska's three federally mandated agencies to plan, advocate, and educate on behalf of people with developmental disabilities.

DE-INSTITUTIONALIZATION

Families of people with mental retardation and similar disabilities have been successful in convincing low-population and small states to move away from large institutions towards home and community based care. "On June 30, 1998 every state except Alaska, District of Columbia, Maine, New Hampshire, New Mexico, Rhode Island, Vermont, and West Virginia was operating at least one large state mental retardation/developmental disabilities facility." (University of Minnesota: May 1999) This national trend continues even though Medicaid expenditures for home & community based services are far lower than payments to institutions. Medicaid programs can be further improved to ensure quality community-based care and supports to the families who care for their relatives with disabilities.

We are proud of the work we have done to de-institutionalize people with developmental disabilities. The state's Developmental Disabilities Planning Council advocated for years to have enough community-based services so that individuals with mental retardation did not have to move to Valdez or Anchorage and live in an institution. The Council worked with Commissioner Perdue's office to first place a moratorium on admissions to the state institution, and with the legislature to find sufficient community service funding. When the Trust was created in 1994, one of

the first actions the Trust made was to pay for the operations of the institutions. This allowed the legislature and Commissioner to re-allocate funds to more effective programs across the state, and to move residents to community. At the same time, Alaska Housing Finance Corporation stepped forward with the capital dollars needed to build the accessible housing required by people who then lived in institutions.

The process took three years. Harborview Developmental Center was closed December 31, 1997. Institutional funds were re-distributed to community-based services, and the Trust ended its funding for the institution. The next year, all of Alaska's private institutions were de-certified, again with a partnership among the Council, the Trust, Alaska Housing Finance Corporation, and providers under the leadership of the Department of Health and Social Services.

The Trust funded a De-institutionalization Impact Study in 1998, which found a net savings of $69,122 per person. Former residents and their guardians rated quality of life as high in most areas. Community based services are meeting their wants and needs, but more than 75 percent still want jobs.

MEDICAID

Of people with developmental disabilities surveyed in 1999, 69 percent have Medicaid; 24 percent receive Medicare. Craciun Research Group (1999) The Beneficiary Survey Project: A Marketing Research Report Alaska Mental Health Trust Authority, Anchorage, Alaska.

Medicaid pays for 70 percent of Alaska's home and community-based care for people with disabilities. Medicaid waivers have changed the lives and circumstances of people with mental retardation and other developmental disabilities. Alaska does not have managed care plans in the way that other states do, but Medicaid waivers that pay for home and community-based care for people with mental retardation and similar disabilities act as managed care. Because of this, people with mental retardation who are eligible for Medicaid waiver services wait on waiting lists for years in Alaska and in other states.

In 1998, Alaska ranked 31st in the country in terms of community services fiscal effort (spending for services per $1,000 of total state personal income). Several studies show that a state's size and wealth is not a determinant of community spending. Alaska has had difficulty participating aggressively in the Home and Community Based Services Waiver program. In Alaska, the Trust paid for a review of Medicaid waivers, conducted by the state's developmental disabilities planning council. The state is in process of streamlining some of the waivers to preserve the individualized services yet pay providers more quickly. Some federal changes could improve Medicaid home and community based service participation as well.

HEALTH CARE

Of people with developmental disabilities surveyed in 1999, 34 percent have been refused medical care because of their situation. 44 percent have trouble getting health insurance. 33 percent went without medical care or had to postpone it for lack of money. Craciun Research Group (1999) The Beneficiary Survey Project: A Marketing Research Report Alaska Mental Health Trust Authority: Anchorage, Alaska.

Public forums conducted in 2000 by the Governor's Council on Disabilities and Special Education brought forward following several major health care barriers: (1) communication with health care staff (38 percent); (2) cost of services (22 percent); and (3) inadequate (or lack of) health insurance. Other health areas they need help with included exercise (24 percent), diet/nutrition (22 percent), stress management (15 percent), and anxiety (13 percent). Governor's Council on Disabilities & Special Education (2000) Anchorage, Alaska.

People with disabilities living in remote areas of the state have particular difficulty accessing health care services. Inadequate and unaffordable health care is major barriers to independent living and employment. The common needs of people with developmental disabilities include durable medical equipment, assistive technology, medicines and personal assistance services. These are rarely fully covered by health insurance. Appropriate mental health and substance abuse treatment are difficult to find because providers rely on cognitive treatment approaches that are not appropriate for people who have mental retardation and similar disabilities.

Medicaid buy-in for people with disabilities Health insurance is inadequate for people with all kinds of chronic health problems. It is particularly difficult for a person who has more than one problem, such as mental retardation and depression or alcoholism. Federal laws permitting insurance parity have helped somewhat in some states, but that has not yet been the case in Alaska. High-risk insurance pools have been as helpful as once hoped.

Alaska is one of the first states to implement the Medicaid buy-in. Starting October 2000, Alaskans with disabilities are able to buy into the state Medicaid program, enabling them to acquire and maintain jobs that do not have sufficient heath insurance to address their disabling conditions. This Medicaid innovation has the potential to help hundreds of Alaskans with disabilities to get and keep employment.

DENTAL CARE

47 percent of respondents with developmental disabilities have trouble getting eyeglasses, dental work or hearing aids. Craciun Research Group (1999) The Beneficiary Survey Project: A Marketing Research Report Alaska Mental Health Trust Authority, Anchorage, Alaska.

Currently, Medicaid coverage of adult dental services is limited under statute to the minimum treatment for the immediate relief of pain and acute infection. This level of service is insufficient to meet the needs of adult Medicaid clients, as no preventive and restorative services or dentures are covered. Many people with disabilities and elders have serious mouth and gum tissue problems due to drug reactions from required prescription medication. There are very few payment options for adult dental services through state or private resources. Tribal health programs have limited resources for the delivery of dental services.

There were 32,384 adults eligible for Medicaid in fiscal year 1999. Of these, 5,670 were elderly and close to 8,000 have disabilities including mental retardation. About 40 percent of adults require periodontal and endodontal work, 25 percent need restorative work (crowns and bridges), and over 3,100 need dentures. All of them need routine preventive services.

FETAL ALCOHOL SYNDROME

Fetal Alcohol Syndrome is a preventable developmental disability. The Trust has invested hundreds of thousands in prevention of FAS through treatment for women, as have the state and federal government. We need to continue this effort, and we need to increase services for individuals who already live with FAS.

SUPPORTED PARENTING

Of people with developmental disabilities surveyed in 1999, 20 percent had children. Half those families had children living out of the home, presumably in state custody. One third of people with mental illness had children under 18 who lived out of the family home, and over one-third of children of alcoholics were also living away from home. Craciun Research Group (1999) The Beneficiary Survey Project: A Marketing Research Report Alaska Mental Health Trust Authority, Anchorage, Alaska.

Parents with disabilities, mental health illness, or severe alcohol problems often need support in fulfilling their parenting responsibilities. Without support, these parents are referred for child protective services (CPS). Alaska needs to:

(1) Prevent child abuse and neglect in families where parents have mental retardation and similar disabilities;

(2) Keep families together with supportive services once a report is made to CPS; and

(3) Work closely with CPS to help reunify the family once a child is removed from his or her home.

With changes in the CPS, it is more important than ever that parents receive an adequate amount of support services to help them fulfill their parenting responsibilities. All families referred to CPS are given a time limit for changing the situation that leading to state involvement. Parents with disabilities are often at a disadvantage since they often need longer time periods and more intensive services that are currently provided.

For parents who are mentally ill, a recent pilot program aimed at diverting them from entering into the CPS is currently underway. Parents who experience a developmental disability and their advocates have been working hard to identify system barriers that increase the risk for having these parents' children removed from their homes. Necessary services include intensive case management with a parenting focus, training to CPS workers on developmental disabilities and case planning.

SUPPORTING CAREGIVERS: FAMILY SUPPORT AND WORKFORCE DEVELOPMENT

Family Supports.—Most people with developmental disabilities (66 percent) receive help from their families. 56 percent have family problems. 62 percent have a hard time taking control of their life. Craciun Research Group (1999) The Bene-

ficiary Survey Project: A Marketing Research Report Alaska Mental Health Trust Authority, Anchorage, Alaska.

Families who care for their disabled members sometimes need support themselves. Twenty-four hour care leads to family problems and can lead to unnecessary institutionalization. Respite care is a crucial break for family members who are doing the right thing. Support groups for parents and siblings of people with mental retardation have proved helpful in developing better relationships and maintaining home situations for people with mental retardation and similar disabilities.

Workforce Development.—High staff turnover, low social status, insufficient training, limited educational and career opportunities, and poor wages undermine the commitment of direct service staff and make it very difficult to recruit, train and retain qualified and committed individuals in direct support roles in disability, mental health, substance abuse treatment and aging fields. The persistence of these conditions is at crisis level.

Alaska's reimbursement for all care providers—particularly in remote, frontier communities—is so low that very few individuals want to take on that kind of job. This demonstrates a very poor regard for people with mental retardation and similar disabilities. To that end, the Trust is working with the state Developmental Disabilities Planning Council and provider groups to develop an industrial consortium, hoping for a federal Department of Labor workforce development grant to bolster daily support to a variety of individuals who have disabilities.

The Alaska Alliance for Direct Service Careers is an emerging coalition of organizations and individuals committed to strengthening the quality of disability, mental health, substance abuse treatment and aging services by strengthening the direct service workforce. The Alliance has developed a state agenda to address those industry-wide conditions that are harmful to people who rely on direct services. Well-planned workforce development strategies are needed to strengthen the direct service workforce.

MENTAL HEALTH COURTS

33 percent of respondents with developmental disabilities have been to jail. More than half (57 percent) of those jailed felt they should have been given medical care instead. Almost 66 percent of people experiencing alcoholism with psychosis, 38 percent of people with mental illness, and 10 percent of people experiencing dementia have been to jail. Craciun Research Group (1999) The Beneficiary Survey Project: A Marketing Research Report Alaska Mental Health Trust Authority, Anchorage, Alaska.

The Alaska Court System instituted the 3rd "mental health court" in the United States in 1999. Two district court judges in Anchorage convened a working group with the Alaska State Troopers, Anchorage Police Department, district attorney, public defender, public guardian, substance abuse treatment agencies, mental health treatment agencies, developmental disability service providers, and the Department of Corrections to find a way to divert the inordinate number of individuals with disabilities from criminal justice instead of necessary treatment. The Court System received its first funding for the mental health court in November 2000 from the Alaska Mental Health Trust.

DEVELOPMENTAL DISABILITIES ACT AND BILL OF RIGHTS

The Developmental Disabilities Act and Bill of Rights (DD Act) is the only Federal initiative that focuses on people with mental retardation and other developmental disabilities. The DD Act has three prongs: Developmental Disabilities Planning Councils, Protection and Advocacy agencies, and University Affiliated Programs in every state and territory. The Protection and Advocacy agencies protect rights in the community and access to health care, the University Affiliated Programs are our best method to develop personnel to work in the field of developmental disabilities. The Developmental Disabilities Planning Council has a special relationship with the Trust as it recommends Trust funding for people with developmental disabilities. Without the Council's guidance, Alaska would not have been the first state in the union with no state or private institutions for the mentally retarded.

The Special Olympics recommendations are a testament to the need for more and better research, individual advocacy, and changes in services at state and federal levels to improve health care for people with developmental disabilities. Many major federal public health initiatives such as Healthy People 2010 focus on preventing & remediating health problems but do not adequately address populations more likely to be affected by the health problems, nor do they adequately address living with chronic health problems. The federal government can require that federally mandated efforts such as Healthy People coordinate with other federally mandated

agencies including Developmental Disability Planning Councils and state Aging commissions.

Just over 10 years ago, Congress required states to prepare a report on the state of people with developmental disabilities, state-by-state. Developmental Disability Planning Councils and University Affiliated Programs conducted these research projects, called the 1990 Report, and the 1990 Report has guided states' disability policy ever since. Perhaps it is time to revisit the 1990 Report and again find out state-by-state what is working and what needs work in the lives of people with mental retardation and similar disabilities.

MORE INFORMATION ABOUT ALASKANS WITH MENTAL RETARDATION AND SIMILAR DISABILITIES

Demographic profile

—Their median household income is above average at $17,628, but their personal income is very low: $7,215 per year.
—15 percent fish or hunt for subsistence.
—An average 32 percent are employed, at least part time or seasonally.
—They get out often (73 percent at least once a week); and 75 percent have activities or hobbies to entertain or express themselves.
—16 percent live in a group home.
—15 percent live with a spouse or cohabit.
—Very few live alone (14 percent); and 47 percent did not decide for themselves where they would live, but an average 45 percent are very satisfied with their living arrangements.
—Many report being happy (29 percent very happy, 42 percent somewhat happy).

Their problems and concerns

—An average 28 percent need more help than they are currently receiving.
—67 percent would like to have more education.
—61 percent receive Social Security.
—62 percent say finding satisfying work is a problem.
—68 percent say they have financial needs that are not covered by existing services.
—74.3 percent do not have enough money.
—55 percent say getting transportation is a problem.
—65.7 percent have trouble finding out about services, and 72 percent have trouble finding the right services in the community.
—51.5 percent need help with legal matters.
—49 percent have trouble finding affordable housing.
—72 percent feel left out of things.
—62 percent say they do not have a decent social life.
—46 percent report physical, emotional, or sexual abuse as a problem.
—49 percent feel unsafe when out and about.
—68 percent say that prejudice is a problem.

Craciun Research Group (1999) The Beneficiary Survey Project: A Marketing Research Report Alaska Mental Health Trust Authority, Anchorage, Alaska.

Senator STEVENS. Thank you very much, Mr. Jessee.

Dr. Kleinfeld.

STATEMENT OF JUDITH KLEINFELD, PROFESSOR, UNIVERSITY OF ALASKA, FAIRBANKS, AK

Dr. KLEINFELD. Senator Stevens, we are deeply grateful for the $29 million fund that you have provided for fetal alcohol syndrome, and to show to you that this investment in Alaska has national and worldwide benefit, I want to draw to your attention and to that of the Surgeon General and Dr. Shriver and to all those here who are working in this area to approaches that have been not tried in the rest of the country, but are showing enormous promise.

The first is a program run by a doctoral student of mine, Steven Jacquier, aimed at the prevention of fetal alcohol syndrome. We can lecture to children all we want, and they do not believe us, but they believe what they see with their own eye, and what Mr. Jacquier is doing is science experiments in classrooms.

He takes laboratory mice, and he force-feeds pregnant mice alcohol with the children. After the pregnancy has reached a later point in gestation, the children sacrifice the mice, and they see what has happened. They see, for example, that instead of eyes, these mice have slits, and sometimes their brains are emerging from their skulls, and then they believe what fetal alcohol syndrome is, and that they and people they know and they love are vulnerable.

We are testing this program, we are documenting its effects, and we think that it offers tremendous advantages not only in the prevention of fetal alcohol syndrome, but also in science education, in laboratory techniques, to children all over the Nation.

The second program that we have developed at the University of Alaska that holds tremendous national promise goes beyond the laboratory scientists, the researchers at the university, people like me who are usually the recipients of Federal grants, and instead taps into the wisdom of people with disabilities themselves.

These two books, which I edited and which I will present to Dr. Shriver, have actually been done by people with fetal alcohol syndrome, by their parents, by their teachers, and they have figured out the most imaginative, the most inventive strategies for dealing with this disability. These are people who work with this every day, who dearly love the children, have done everything in their power and in their lives to figure out what works, and sometimes they come up with things that are a whole lot better than scientists who are the recipients of Federal grants. We need, as a scientific community, to enlarge our appreciation of what knowledge and wisdom is, and to include what I have termed the wisdom of practice.

I would like to conclude by mentioning one area where there is still a tremendous problem, and very little progress, and that is young people with fetal alcohol syndrome are very often in trouble with the law, and particularly, and I will say it, difficult as it is, this terrible area of sexual molestation and sexual abuse, and there are reasons for this.

For one thing, to young people, fetal alcohol syndrome means cognitive disability. They cannot predict the results of their actions. They have a very difficult time controlling their impulses. They are more comfortable with younger people, and they can repeat the rules. I have heard them repeat the rules, and they do not understand what these rules mean, so the authorities think they are just disobeying.

Our legal system does not have the appropriate categories to deal with people with this type of diminished capacity. They do not have the type of support or incarceration facilities. Frequently, what happens is, the young people are exposed to people who just model for them worse things to do, and when out on parole, their memory lapses mean they forget to see their parole officer.

PREPARED STATEMENT

One of the great areas of need is to bring together the law enforcement community and to see what can be done to adjust the sentencing guidelines of categories to assist those who deal with these people protect themselves and also protect the community.

Thank you.
[The statement follows:]

PREPARED STATEMENT OF JUDITH KLEINFELD

INTRODUCTION

Senator Ted Stevens deserves enormous appreciation from us all for his hard work and his foresight in securing a five-year, $29 million grant for the state of Alaska to prevent fetal alcohol syndrome and to assist those who suffer from it.

Senator Stevens is helping to prevent what happened to young boys like "Oscar," in southwest Alaska, from happening to others. This is a terrible tale:

At 15 years old, Oscar made the high school track team. He was just delighted. This was one of his few successes and he was excited.

His adoptive mother told the coach he had fetal alcohol syndrome, and that FAS makes memory come and go. She told the coach never to let Oscar walk home alone after track practice without his older brother.

But Oscar would sometimes forget about practice. He sometimes forgot his track shoes. The coach left him alone in the parking lot after practice and made no accommodations for his disability.

Oscar did not feel welcome on the track team. He did not feel welcome anywhere. When he was sixteen years old, Oscar committed suicide.

The Alaska Department of Health and Social Services is managing the funds for FAS with seriousness and skill. Today I want to draw attention to Alaska's pioneering accomplishments in two areas of prevention and education so that other states may benefit from them. I also want to draw attention to unmet needs:

Trouble with the Law.—FAS is a significant problem for many alcohol-affected individuals accused of crimes because FAS affects people's ability to understand the results of their actions and FAS affects people's abilities to resist their impulses.

Supported Employment and Living.—Most adults with FAS can not live successfully on their own. They need supported living environments and they need job coaching.

Mental Health Needs.—Many individuals with FAS are angry and depressed, sometimes suicidal, and need mental health support.

THE GOOD NEWS: MANY PEOPLE WITH FAS DO WELL WITH SUPPORT

While the problems of FAS are severe, we should beware of stereotyping people with FAS. Some people with fetal alcohol syndrome, with support, are graduating from college and vocational programs and holding paying jobs (Kleinfeld, 2000). Many have special strengths, for example, in working with animals and succeed in modified jobs in veterinary clinics and grooming businesses.

The ability of people with FAS to live fully in the present is the opposite side of their problems in understanding the future. Many of us forget to savor the present in our pell-mell rush through life and allow the beauty and delights of everyday moments to slip through are fingers. People with FAS have something to teach us all.

FETAL ALCOHOL SYNDROME IS THE LEADING KNOWN CAUSE OF MENTAL RETARDATION

A person with Fetal Alcohol Syndrome suffers from a permanent birth defect that is caused by excessive maternal consumption of alcohol during pregnancy. The most destructive form of alcohol abuse during pregnancy is binge drinking.

FAS is characterized by: (1) pre- and post-natal growth deficiencies that place a child below the tenth percentile for height or weight or both, (2) a distinctive pattern of facial features, and, most importantly (3) damage to the central nervous system. A person with all three features is considered to have fetal alcohol syndrome. A person with one or two of these features, usually the damage to the central nervous system, is considered to have Fetal Alcohol Effects.

FAS is the leading known cause of mental retardation. Twenty-five percent of people with FAS and 10 percent of people with FAE have IQ scores of 70 or below, in the mentally handicapped range (Streissguth 1997, p. 103).

But it is a great mistake to think that people with FAE are better off than people with FAS. This point should be underscored. FAE is not a less severe form of FAS. In fact, children with FAE often experience worse problems because they lack many of the outward signs of FAS and people do not understand they are brain damaged. A young person with FAE, for example, may be able to repeat a school rule. But he may break the rule because he does not really understand what the rule means.

ALASKA HAS THE HIGHEST INCIDENCE OF FETAL ALCOHOL SYNDROME IN THE NATION

The prevalence of Fetal Alcohol Syndrome in Alaska is estimated at 1.0 to 1.4 per 1000 births, while the national average is estimated as 0.1 to .7 per births (State of Alaska, 2000). Over 20,000 Alaskan women of childbearing age acknowledge that they are heavy drinkers and seven percent of new mothers said that they drank alcohol during the third trimester of pregnancy (DHSS Report #1, 1997, p. 5, cited in Kleinfeld, 2000).

ALASKA HAS PIONEERED WISDOM OF PRACTICE STUDIES THAT REVEAL WHAT WORKS

At the University of Alaska Fairbanks, my research team has pioneered "wisdom of practice" studies where we work with parents, teachers, counselors, and young people with Fetal Alcohol Syndrome to figure out what helps. We have identified a wealth of educational techniques that help individuals with FAS (Kleinfeld & Wescott, 1993; Kleinfeld, 2000).

"Take 'Karen' who has FAS and wanted to be a bridesmaid at her sister's wedding. She knew her hyperactivity wouldn't let her stay still from the ceremony to the wedding pictures. On her own, she came up with an idea; Bring sweats and running shoes and run off her energy between the wedding and the photographs."

ALASKA HAS DEVELOPED A PROMISING "SCHOOL AND MICE-BASED" APPROACH TO PREVENTION

One of my doctoral students, Steven Jacquier, has developed a school-based approach to preventing fetal alcohol syndrome which looks very promising.

As CNN described it:

"Where the mouse should have a paw, it has a flipper, with fused bones instead of toes. Where the mouse should have an eyeball, it has no orb, only a tiny hole in its skull.

"Stephen Jacquier's high school science students perform Caesarean sections on pregnant lab mice that have been force-fed alcohol. As the students dissect the amniotic sacs, they get a startling view of how booze can affect the unborn.

"'We may also see the brain sticking out of the top of the head,' Jacquier says. 'You may also see limbs missing.'"—CNN.com.health. December 18, 2000.

This approach lets students see with their own eyes the effects of alcohol during pregnancy and draw their own conclusions. Jacquier is documenting large gains in knowledge and positive shifts in attitudes and beliefs about drinking.

THE FAS FRONTIER: WHERE WE NEED TO GO

Trouble with the Law

FAS is a significant problem in criminality because this biological condition "affects a person's ability to plan their conduct or, conversely, to resist impulse" (Dagher-Margosian, 1997, p. 125). Currently no information exists on the number of alcohol-affected individuals in Alaskan prisons or what special accommodations are being made to meet their needs as mentally disabled individuals. Little to no research has been conducted into what percentage of repeat offenders are alcohol-affected and what can be done to support FAS offenders in successfully meeting probation and parole requirements. Many people in the criminal justice and corrections system in Alaska are aware of the high incidence of FAS but most do not know what needs to be done to help clients.

Recommendation.—A state-wide forum to discuss FAS and the criminal justice system needs to take place.

Supported Employment and Living

People with FAS need support to manage their daily lives. Some do well with help from their parents, siblings, or spouses (Kleinfeld, 2000). But others need supported living environments where other people assist them in meeting the demands of a day (Streissguth, 1997, p. 203). Currently, no specific assisted living environments for people with FAS exist in Alaska.

Recommendation.—Funding sources and training need to be made available for families and communities to explore group homes and other forms of supported employment and living.

Mental Health Needs

Many individuals with FAS become angry and depressed, sometimes suicidal, and need mental health support. Counselors often feel, mistakenly that they don't have the skills to deal with clients with FAS (Kleinfeld, 2000, p. 340). Many do not real-

ize that insight therapies and other strategies they use can be easily adapted to the visual, concrete learning styles of people with FAS (Baxter, 2000).

Recommendation.—More mental health services need to be made available, especially to adolescents, to promote better life outcomes and especially to prevent suicide.

CONCLUSION

Alaska is making a difference in the prevention and management of FAS and offers a beacon light to other states. Tomorrow holds a great deal of promise because of what we are doing together today.

Senator STEVENS. Thank you very much.

Karen, I hope that you saw the bill that Congress passed last year that I authored to start physical education concepts again in grades K through 12. There are only five States who are going to get provisional grants. I hope you quickly make an application.

But I look forward to working with you, and I think we ought to have a counsel group one of these days as sort of a get-together of those of us in Washington and some of the State legislators that deal with these issues you three have just mentioned. I think we might be able to find better coordination between the Federal and the State and local efforts in this regard if we could.

So I thank you very much. I had a whole bunch of questions in my mind, but I think we had better move on to finish the other panels, so thank you all very much for coming.

INTRODUCTION OF MS. CLAIBORNE AND MS. MARIN

Our next panel is Loretta Claiborne, Rosario Marin, councilwoman from Huntington Park, California, and we will have two other people who wish to testify, and then we will listen to Mr. Schwarzenegger, so let us go with these witnesses first.

Let me introduce Ms. Claiborne, a native of Pennsylvania, a gifted long distance runner, an all-around athlete. She completed several marathons, and holds a black belt in karate. She has received countless awards and honors, the Arthur Ashe Award for Courage, the Athlete of the Quarter Century Award from Runner's World, she was selected by the U.S. Olympic Committee as a member of its prestigious Project Gold program, and she is also a very distinguished speaker. I listened to her speak at a luncheon in Washington.

Ms. Claiborne, please.

STATEMENT OF LORETTA CLAIBORNE, PA, SPECIAL OLYMPICS ATHLETE AND GLOBAL MESSENGER

Ms. CLAIBORNE. Thank you very much, Mr. Chairman.

Good morning. My name is Loretta Claiborne. I appreciate your willingness to conduct this hearing and to allow me to offer testimony about the health needs of persons with mental retardation. I want to tell you a little bit about my life, because I believe it paints a picture of how difficult it is for persons with mental retardation to get good health care.

You may have seen the Loretta Claiborne Story, which aired on ABC last year. This made-for-television film was created by Disney. It is a pretty accurate summary of many of the challenges I faced while I was growing up. A number of these challenges were medical in nature. I remember only too well the visits to the clinics and

the doctors. I remember being afraid of and unsure about what would happen or not happen every time I saw a doctor.

I am going to stop reading this statement at this time, because No. 1, if it was not for Special Olympics, I would not be sitting here. No. 2, I remember back to when I was a child, and my mother took me to a doctor for my feet, and the doctor looked at her and said, because she was poor, after we had sat in the clinic for hours upon hours—we used to take our lunch, and I used to take my knitting—the doctor looked at her and said, "you know what these retarded kids dream. Take her home and smack her on the butt and then she won't walk on the side of her feet."

She brought me back to the clinic again. The doctor looked at her and said, Mrs. Claiborne, you have been sitting here for 5 hours, come back to my room. I'm going to give this child an X-ray, and he found out I had bad sesamoid bones and they operated on my feet. Years later, I had my eyes operated on. I read with my left eye, and I look for distance with my right.

I grew up, my mother passed away, and here is Loretta, left fighting for herself. In 1995, I was diagnosed with a tumor in my stomach. The doctor looked at me, and I kept saying to her I was gaining weight. I said, Dr. McMillan, how can I gain 20 pounds in 4 months, with all this running I am doing, I am eating right. I am taking care of myself. She said, "oh, you're just getting older."

I looked at her and said, I am not going to buy that, and I persuaded her. I said, could I please have a physical. She put me up on the table, she gave me a pelvic. She looked, she said, "oh my God, Loretta, go to the hospital real quick, as quick as you can." I went to the hospital, they put me in the mother-child clinic. The guy looked at me—he was so rough. He didn't understand my needs. I looked at him, put my clothes on, I said, I ain't got time for you. I went back to my doctor, and I had to fight to go to Hershey Medical Center. Eleven months later I had the tumor taken out. I was the size of a 7-month pregnant woman when I went to the 1995 Games. That September, it was removed. Why didn't they take care of it when it was small?

Doctors listen, people listen. It is a shame what our people are going through. As it was said here earlier, if you make a couple of pennies over, you lose your medicaid, then you end up in what they call HMO's. I have a bad leg; my leg, I have hurt it. I have had to come to this State to get an X-ray after begging my doctors back home, because they would not do it. Here in Alaska, they found out that I had a torn meniscus. The doctors from this State told me to go back home and get it fixed. My doctor says, he is not going to operate on my leg and fix it.

You know what is going to happen, society is going to pay for that leg years later when I have arthritis. Society is going to pay for things that we do not take care of for our people with mental retardation. One day I went to the clinic and I saw a friend of mine, who is incarcerated. He was getting his teeth fixed. I have to go to the dentist every 3 months, between a dentist and a periodontist, because I need the medical care, and I have to take my little food money to pay for my teeth. It is a shame in our society. It is a shame in our world. It is a shame in the good, old United States that this has to happen.

I have never committed a crime in my life. My people have never committed a crime. What are we doing about it? Hardly anything. Please, people, be sensitive. We do more for our people who are incarcerated than we do for our people who have never committed a crime, who are just trying to live out their lives the best they can live them out.

Special Olympics has been my key to my door to take care of my health. At my age, my mother had one foot in the grave. At 63, she was dead, because she smoked. I do not smoke. I do not do tobacco. I take care of my body.

PREPARED STATEMENT

The Special Olympics has told me, has gave me a hope and thought that, Loretta, you are going to live a long life if you take care of your body, and the Special Olympics keeps me motivated, because I want to be a good athlete. I have run 26 marathons, I am a fourth degree black belt and I enjoy life, and all I want to do is live in society.

Thank you very much, good luck, and God bless.

[The statement follows:]

PREPARED STATEMENT OF LORETTA CLAIBORNE

Good morning. My name is Loretta Claiborne. Mr. Chairman, I appreciate your willingness to conduct this hearing and to allow me to offer testimony about the health needs of persons with mental retardation.

I am a person with mental retardation. I also am a longtime Special Olympics athlete, global messenger and volunteer. As you look at me sitting here, you might say that I appear to be reasonably healthy. And I would agree with that. I have trained and competed in a number of sports since I was a teenager. I have been fortunate enough to win numerous medals from my competitions and to even set a few records.

I want to tell you a little bit about my life, because I believe that it paints a picture of how difficult it is for persons with mental retardation to get good health care. You may have seen "The Loretta Claiborne Story" which aired on ABC last year. This made-for-television film created by Disney is a pretty accurate summary of many of the challenges that I faced while I was growing up. A number of these challenges were medical in nature. I remember only too well the visits to clinics and doctors. I remember being afraid and unsure about what would happen or not happen every time I saw a doctor.

As a child, in addition to the regular childhood illnesses, I had some serious health problems, including a bad foot that barely allowed me to walk, let alone run; and, severe problems with my eyes that made it difficult for me to understand what was gong on around me. I was shy and withdrawn, not speaking until age 4. I was fortunate, however. My mother and other people that cared about me fought hard to get me the corrective care that I needed. Clearly, that has turned out to be a good investment in me and a good investment for society.

In addition to caring individuals, I must thank Special Olympics for being there for me. The organization gave me a chance to feel accomplishment and value. Special Olympics gave me a reason to push myself to levels of athletic accomplishment and good health that I otherwise never would have even attempted.

I have to say that things have not come easy for me. I was a pretty stubborn person when I was young. But, I eventually learned how to turn stubbornness into persistence to get what I wanted. Part of what I wanted was personal success. Today, I am a recognized athlete. My story has motivated others. I have reasonably good health. People care about what I have to say and invite me to make motivational speeches. And, my contributions count. This may not seem like a lot to some people, but it is a lot to me. I want other people with mental retardation to have these same opportunities to contribute and succeed, which means that they must have good health.

Today, I am pretty much of a health addict. I run and exercise regularly. I watch what I eat, because weight has been an issue for me and others in my family. No tobacco or alcohol for me—I am a serious athlete. And, I go to the doctor at the early

signs of any problem. Also, I brush and floss my teeth every day. I am very focused on this because I have a tendency to get gum infections.

But, I still have health challenges and have to fight the system every time I need medical attention. I have had a tumor misdiagnosed and mistreated. I have ongoing knee problems. These conditions are not related to mental retardation; they are common medical problems that don't require doctors to be experts in caring for a patient with special needs. They are medical problems that just require a doctor to want to treat a person with disabilities.

Mr. Chairman, please understand that all people with mental retardation will not have the same level of confidence, capability or resolve that I have. Not all people with mental retardation necessarily have the support system and advocates that I had. And, unfortunately, people with mental retardation still face a lot of intentional and unintentional discrimination. We want people to think that it is important that we are not just not sick, but to help us to be as healthy as we can be.

This means that people need to have high health expectations for each one of us, regardless of our underlying health challenges. It means that doctors and dentists and other health providers must understand our needs and be willing to give us the type of care we need. It means that the people who pay for care must not shortchange our health care providers or we will get shortchanged.

It is my hope and dream, that within the decade, no person with mental retardation will live one day less, because they were denied some treatment or care that was available to others. And, finally, I want everyone to know that while I and others like me may learn slower or in different ways, that does not mean that we are stupid or that we do not care about our health. When you design health education materials, think about us. When you create web pages, think about us. When you teach doctors about caring for patients, think about us. And when you ask for opinions as to problems and solutions, ask us, just like you are doing today.

God bless you in these efforts and for chairing this hearing.

Senator STEVENS. Thank you very much. It is nice to see you again, and I look forward to working with you.

Ms. Marin is council member for the City of Huntington Park, California. She recently completed a term as the city's mayor. Councilwoman Marin has served as the chair of the California State Council of Developmental Disabilities, and the Chief of Legislative Affairs for the State Department of Developmental Services, and as Special Education Commissioner for the Los Angeles United School District, and it is nice to see you here. Thank you very much.

STATEMENT OF HON. ROSARIO MARIN, COUNCILWOMAN, HUNTINGTON PARK, CA

Ms. MARIN. Thank you. Mr. Chairman. I certainly appreciate the opportunity to speak with you if only for a few minutes about a subject that for the last 15 years has been my life's mission, and that being the health needs of people with mental retardation.

First and foremost, I am the mother of a 15-year-old handsome young man with Down's Syndrome, who because of serious medical conditions cannot participate in Special Olympics. Regrettably, it could have been prevented.

In addition, I am a member of Special Olympics board of directors and, as you stated before, I have worked for the State of California in different capacities.

Senator, the arrival of a new child in the family is always a highly emotional time. Ninty-seven percent of the time, it is a period of enormous joy. Most celebrities cite the birth of a child as the happiest event of their lives. As you can only imagine, the birth of a child with mental retardation is probably one of the most difficult times a family can endure. The parents' dreams are shattered in one second.

Sometimes, as in the case of Down's Syndrome, it is apparent right away. Sometimes, with other disabilities, it slowly becomes apparent as a child starts school. Nevertheless, the confirmation of a diagnosis often triggers feelings of immense grief, of hopelessness. Oftentimes, they are overwhelming.

And yet, after the diagnosis, families and their children with mental retardation fight an uphill battle all the way. While mental retardation affects all stratas of society and all countries in the world, its effects lie more heavily on those sectors where poverty is most prevalent, the undereducated, underemployed, underinsured, malnourished, poorly housed, including many people who are ethnic and racial minorities.

Unhappily, these people generally do not have the resources to fight the relentless fight to get attention and support for their children, this applies across the board in terms of education, social services and effective diagnosis, preventive and corrective health services, and just because it is written somewhere that a person is eligible for services, this does not mean at all that they will receive it.

Given that they are the most vulnerable to the effects of these diseases and conditions, and have limitations in their ability to advocate for themselves, we should be providing the highest level of care, and caring for them. After all, Senator, our goals should not be just to say that there was something in place, but rather that something was actually done for them.

It is my profound belief as a parent and as a public official that people with mental retardation have a fundamental right to decent treatment in and by our health care system. This means health care programs need to be designed to meet the needs of patients and families. It means that payment mechanisms and payment levels should be adequate to interest providers and to motivate them to provide quality care.

This means that clinical outcomes should be monitored more closely than simply cost minimization. If you look into the report that Special Olympics developed concerning the health status and needs of persons with mental retardation, it is clear that both children and adults with mental retardation are getting far less in terms of health assessment and health care than they need, and that they deserve.

Given the laws that have been enacted in this country and in many countries to prevent people with disabilities from being discriminated against, or denied access to basic human rights, we clearly have a problem. This is a problem that has been shadowed in obscurity long enough. The time has come to shed light on what properly could become a scandal. People with mental retardation suffer unnecessarily from preventable and manageable diseases and conditions. Their lives are shortened. Their dignity is diminished, their opportunities unduly denied, including meaningful social participation, and their families, in many cases, experience feelings of helplessness and frustration that go along with it.

This hearing is a beacon of hope. We need sustained actions to follow, Senator, better policies, and more resources at all levels, but at a minimum, how about ensuring the provision of services for which they are already eligible, the ones they are legally entitled.

We need better trained health care providers who receive didactic and practical experience working with patients with mental retardation of all ages, not just children.

In that regard, I believe that the school-based individual education plans mandated by law for persons with disabilities should include provisions to assure necessary health care. For what person, child or adult, can concentrate on learning when they are dragged down by a constellation of health problems.

PREPARED STATEMENT

Senator Stevens, I want to thank you for your attention. It is my sincere hope that this will be the first step in a true commitment to improve the lives of people with mental retardation, and with it, the ability of the society to become enlightened, for it has been said before that a society is judged by how it treats its most vulnerable. I pray to God that he gives us the strength to fight the good fight for people like my son, Eric, so that at the end of the day we can all be proud of our collective good.

Thank you, Senator.

[The statement follows:]

PREPARED STATEMENT OF ROSARIO MARIN

Mr. Chairman, I greatly appreciate the opportunity to speak with you, if only for a few minutes, about a subject that for the last 15 years has been my mission and clearly it is very close to my heart—that being the health needs of persons with mental retardation.

First and foremost, I am the mother of Eric, a 15 year-old handsome young man with Down syndrome, who because of a serious medical condition cannot participate in Special Olympics. Regrettably, it could have been prevented. In addition, I am a member of the Special Olympics Board of Directors. And furthermore, I have served the State of California in a number of capacities, including a term as Chair of the California State Council on Developmental Disabilities. I also served as a member of the Special Education Commission for the Los Angeles Unified School District.

Senator, the arrival of a new child in a family is always a highly emotional and tumultuous time. Ninety-three percent of the time is a period of enormous joy. Most celebrities cite the birth of their child as the happiest event of their lives. As you can only imagine, the birth of a child with mental retardation, is probably one of the most difficult times a family can endure. The parents' dreams are shattered in a second. Your whole world is turned upside down. Sometimes as in the case with Down syndrome, it is apparent right away, sometimes with other disabilities, it slowly becomes apparent as a child starts in school. Nevertheless, the confirmation of a diagnosis often triggers feelings of immense grief; the helplessness and hopelessness oftentimes are overwhelming.

Families and their children with mental retardation fight an uphill battle all of the way. While mental retardation affects all strata of society in all countries of the world, its effects fall more heavily on those sectors where poverty is most prevalent—the undereducated, underemployed, underinsured, malnourished, poorly housed, including many ethnic and racial minorities.

Unhappily, these people generally do not have the resources and personal access, connections and confidence to fight the relentless fight to get attention and support for their children. This applies across the board in terms of education, social services and effective diagnostic, preventive and corrective health services. And, just because it is written down somewhere that a person is eligible for a service, this does not mean that they will receive it.

I am not a health expert, but I know from the experience that I have had with my son and from talking to other parents of children with mental retardation that we as a country and our health care system, its providers and insurers and payers, are not doing right by these individuals.

Given that they are the most vulnerable to the effects of diseases and conditions, and have limitations in their ability to advocate for themselves, we should be providing the highest level of care and caring for them. After all, our goal should not

be just to say that there was something in place, but rather that something got done for them.

It is my profound belief as a parent, public official and advocate for individuals with mental retardation and their families that they have a fundamental right to decent treatment in, and by, our healthcare system.

This means that care programs need to be designed to meet the needs of patients and families first rather than bureaucracies. This means that payment mechanisms and payment levels should be adequate to interest providers and to motivate them to provide quality care. This means that clinical outcomes should be monitored more closely than simply cost minimization. This means that providers should have expectations for persons with mental retardation in terms of quality life years and meaningful health promotion opportunities.

If you look into the report that Special Olympics has developed concerning the health status and needs of persons with mental retardation, it is clear that people with mental retardation, both children and adults, are getting far less in terms of health assessment and health care than they need and deserve. Given the laws that have been enacted in this country and in many others to prevent people with disabilities from being discriminated against or denied access to basic human rights, we clearly have a problem. This is a problem that has wallowed in obscurity long enough.

The time has come to shed the proper light on what properly could be called a scandal. People with mental retardation suffer unnecessarily from preventable and manageable diseases and conditions. Their lives are shortened; their dignity is diminished, their opportunities unduly denied, including meaningful social participation. And their families deal, in many cases, with the feelings of helplessness and frustration that go along with this.

This hearing is extremely important for bringing critical issues to light.

We need sustained actions to follow—better policies and more resources at all levels. But at a minimum, how about assuring the provision of services for which they are already eligible, the ones to which they are legally entitled?

We need better-trained health care providers who receive didactic and practical experience working with patients with mental retardation of all ages.

We need care managers who see the patient not just through a specialty treatment, but toward an integrated clinical and functional goal. We need health care for persons with mental retardation viewed as a critical mediator of how a life will be lived.

In that regard, I believe that the school-based individual education plans mandated by law for persons with disabilities, should include provisions to assure necessary health care. For what person, child or adult, could concentrate on learning when they are dragged down by a constellation of health problems, including vision deficits, dental care needs, hearing problems, hypertension, diabetes, seizures and so on?

Senator Stevens, I want to thank you for your attention. It is my sincere hope that this will be the first step in a true commitment to improving the lives of persons with mental retardation, and with it, the ability of this society to become enlightened. For it has been said before that a society is judged by how it treats its most vulnerable. I pray to God that he gives us the strength to fight the good fight for people like my son Eric, so that at the end of the day, we can be proud of our collective good.

INTRODUCTION OF DR. PERLMAN AND MR. ERVIN

Senator STEVENS. Thank you very much. We are going to add two witnesses, Dr. Steven Perlman, and Mr. James Ervin. Would you come and join us here, please?

Dr. Perlman is the global clinical director for the Special Olympics Special Smiles program. He is an associate clinical professor of pediatric dentistry at Boston University, and has asked to make a few comments concerning access to dental care.

Mr. Ervin, James E. Ervin from Albany, GA, is immediate past president and chairman of the board of trustees of the International Association of Lions Clubs. Mr. Ervin spent the last 5 years as an executive officer traveling around the world on behalf of the Lions Clubs International, and he has worked in partner-

ships to enhance the Lions' humanitarian objectives, and particularly as it pertains to blindness.

We are happy to have your testimony, Dr. Perlman. We have still got to get to Mr. Schwarzenegger, so please, if you will, make your comments as short as possible.

STATEMENT OF DR. STEVE PERLMAN, GLOBAL CLINICAL DIRECTOR, SPECIAL OLYMPICS, SPECIAL SMILES PROGRAM

Dr. PERLMAN. Mr. Chairman, please allow me to represent the health care professionals who do care. For over 25 years we have joined forces to fight the battles in our professional schools, to increase the training of health care providers in treating people with mental retardation.

As you know, it is nearly impossible to enact curriculum changes. We have fought for changes in reimbursement levels with medicaid, medicare, and private insurance companies, but you know how hard it is and difficult it is to engender change there.

In the words of a Special Olympics slogan at the last World Games, it is all about attitude. We have shown that no matter how much education that we give providers, no matter how much we pay them, it still does not increase access to care. It is all about attitude.

But your presence here at this congressional hearing, and Dr. Satcher's presence here, his time over the last 2 days to meet our health care providers and listen to the families, their athletes, their stories, you have shown the world that our elected representatives can and do care. You are giving those of us who are health care providers, the biggest opportunity to make a change that I have personally witnessed in my entire professional career.

Dr. Satcher's commitment to hold the first-ever Surgeon General's conference on health care issues for individuals with mental retardation is an unbelievable first step in our long road to improving the quality of life for people of the world with mental retardation.

Thank you.

Senator STEVENS. Thank you, Dr. Perlman.

Mr. Ervin.

STATEMENT OF JAMES E. ERVIN, ALBANY, GA, LIONS CLUB INTERNATIONAL

Mr. ERVIN. Thank you, Mr. Chairman. It certainly is a pleasure to be here and have an opportunity to join all of our distinguished people at this hearing. Today, I would not only like to represent Lions Clubs International, the world's largest humanitarian service club, I am here today as a volunteer, and I want you and the Surgeon General to understand how important it is for us as volunteers to be heard, because we are working in our communities not only throughout the United States, but around the world, to improve the quality of life for people most in need, and that certainly includes all of our friends who have mental retardation.

You mentioned earlier that we have been working in blindness prevention, and that is what brings us here as a partner in Special Olympics, is the Opening Eyes programs. When Dr. Tim Shriver came to us and shared with us the opportunity that to become involved with vision care for people with mental retardation, we

knew it was natural for us to accept this challenge, because in 1925, Helen Keller challenged the Lions to become Knights of the Blind in the crusade against darkness.

She also was asked in an interview, could she imagine that there was anything worse than being blind, and she said, yes, to have sight, but no vision. We are here today because Mrs. Eunice Shriver had a vision, a vision to help these athletes with mental retardation. We have tried to live up to our vision in blindness prevention to help eliminate preventable and reversible blindness around the world.

Dr. Satcher mentioned that he felt it was important to create partnerships. We have provided $3.2 million to help Special Olympics in funding the Opening Eyes program. Last year, our association spent more than $41 million in humanitarian services and disaster relief around the world, and we are asking you, as Congress, Dr. Satcher, and those, to come to the table as our partners, as volunteers, as people working in nongovernmental organizations, who are working as volunteers to improve the quality of life, to make our communities a better place to live and to raise our families.

We hear every day on the news about the more than $5 trillion that we are arguing about what we are going to do with over the next 10 years, or the surplus. We ask you to consider bringing some of that funding to the table with us so that we can share in helping those most in need. Thank you.

Senator STEVENS. Thank you. I am pleased you came forward, Mr. Ervin. We look forward to working with you, and I have a particular reason for working with you, too, so I will be glad to talk to you about it.

Mr. ERVIN. Thank you, sir.

INTRODUCTION OF MR. SCHWARZENEGGER

Senator STEVENS. Thank you very much. We will now ask Mr. Schwarzenegger to join us and complete our hearing this morning.

I do not think you need any introduction, but I will tell the audience that you served as President George Herbert Walker Bush's chairman of the President's Council on Physical Fitness. Mr. Schwarzenegger is Special Olympics honorary torch bearer, travelling the world to promote Special Olympics sports programs.

Mr. Schwarzenegger's film career I am sure we all know, and I am one of your devoted followers, Mr. Schwarzenegger, The Terminator, True Lies, Kindergarten Cop, The Twins—I am delighted to see you here with your wife Maria, and I thank you for all you have done for the Special Olympics. We saw you lead the group in last night from Austria, and it is nice of you to take the time to be with us. You can terminate the program whenever you are ready.

STATEMENT OF ARNOLD SCHWARZENEGGER, CHAIRMAN, PRESIDENT'S COUNCIL ON PHYSICAL FITNESS

Mr. SCHWARZENEGGER. Thank you very much, Mr. Chairman, and I first of all want to just say congratulations, and thank you for the outstanding job that you have done, and that your son Ben has done here for Special Olympics in Alaska, and especially on the

opening ceremonies. As I said yesterday, they were absolutely mind-blowing. They were fantastic, so congratulations.

Senator STEVENS. I will give my son Ben the applause.

Thank you very much.

Mr. SCHWARZENEGGER. Mr. Chairman, distinguished members of the audience, and most particularly, the Special Olympics athletes and their families, I am grateful and honored to testify before this committee today. There are two things near and dear to my heart: The importance of physical fitness, and creating a healthy lifestyle, and Special Olympics. Thanks to your vision and leadership, Mr. Chairman, both are the subject of this unprecedented hearing on the health status and needs of individuals with mental retardation.

Thirty-five years ago, children born with mental retardation were sentenced to institutions, where they were often restrained in beds for days at a time. Parents were told by medical professionals that their child would never learn, could never read, never feed themselves, and never, never would they be able to participate in physical activities or in exercise, yet one woman with a vision refused to accept these expert predictions.

In spite of the skeptics, and notwithstanding the stigma and fear that surrounded this population, Eunice Kennedy Shriver instinctively knew that individuals with mental retardation could run and jump and throw a ball, and even swim, so she invited them to a camp in her backyard, along with coaches and college students, and soon these individuals were running, riding horses, and playing ball.

Eunice Shriver's vision extended to the creation of an organization whose mission statement calls for year-round sports training and athletic competition in a variety of Olympic-type sports for children and adults with mental retardation, giving them continued opportunities to develop physical fitness. Thus, Special Olympics was born, and you cannot even begin to imagine how far it has come. Well, we have seen it yesterday.

Today, 1 million people with mental retardation participate in Special Olympics around the world. This week, nearly 2,000 Special Olympics athletes will compete at its World Winter Games before a global audience. Everywhere I travel, from Southern California to my homeland, Austria, to China, I see the power of Eunice Shriver's vision.

I see athletes completing marathons in less than 3 hours. I see athletes bowling perfect games. I see Special Olympics athletes speaking out, coaching kids, and officiating at world-class events.

Last year, Special Olympics athletes joined me as we lit the flame of hope at the Great Wall in Beijing. Later, I was joined by athletes in meeting President Jang Zemin, where we asked for Government support of programs intended to improve the quality of life for people with mental retardation in China, the same country where not long ago, children born with mental retardation were often left to die so parents could have, a "normal baby" pursuant to the one-child-per-family policy. President Jang Zemin promised he would help.

Notwithstanding the life work and vision of my inspirational mother-in-law, the harsh statistics and data contained in this report are sobering. People with mental retardation live an average

of 10 to 20 years less than the general population. Individuals with mental retardation suffer from a wide range of chronic and acute diseases and conditions.

In many instances, they experience more frequent and severe symptoms than the general population, including heart disease, diabetes, obesity, respiratory problems, mental illness, vision deficits, hearing deficits, and oral health problems.

Mr. Chairman, we can and must do something to address the health deficits of people with mental retardation. We are now at a point that virtually all leaders in the health field and a large portion of the general public understands that being healthy is more than just not being actually ill. We understand that regular physical activity reduces the risk of dying from coronary heart diseases, and of developing high blood pressure, colon cancer, and diabetes.

We know that for people with disabling conditions, regular exercise can improve their stamina and muscle strength, but as much as the American public also knows, establishing and maintaining fitness is not simple, not short-term activity. It is not a short-term challenge. It is a lifelong requirement for a healthy, productive life.

Moreover, despite the increased focus on personal and general population health promotion and disease prevention both in the United States and elsewhere, this report points out that persons with mental retardation have received very little consideration. In fact, since this population is more likely to encounter secondary health problems like coronary diseases or obesity, it makes sense that health promotion and physical fitness will particularly benefit people with mental retardation.

Therefore, I believe that a broad public assessment of people with mental retardation needs to be undertaken by leading public health and professional organizations. The new National Center on Birth Defects and Developmental Disabilities at the U.S. Center for Disease Control and Prevention should have an explicit program focus and added resources to fund research and programs on prevention of secondary disabilities among persons with mental retardation.

I also believe that the President's Council on Physical Fitness and Sports, which I had the privilege to serve on under President Bush, should specifically focus on the needs of people with mental retardation. In fact, I call on the new President Bush to appoint a person with mental retardation to the Physical Fitness Council and, if he needs any suggestions, I would recommend very strongly my very dear friend Loretta Claiborne, who was testifying here earlier today.

Sports organizations like Special Olympics should forge ahead, too. Too often, lack of appropriate regular exercise and physical activity regimes, in spite of participation in Special Olympics, leave many athletes far short of desirable personal physical fitness standards. Accordingly, I am especially pleased that an athletes health promotion center is being pilot-tested right here at the Special Olympics World Winter Games to teach athletes about wellness and healthy lifestyles. I encourage you to stop by the Olympic Town and take a look, Mr. Chairman.

PREPARED STATEMENT

In closing, Mr. Chairman, I am ready to help you in any way possible to address the findings contained in this report, and to work with you to improve the quality and the length of life for people with mental retardation. In short, I am here to help you terminate the problem.

Thank you for the opportunity to share my views. Thank you very much.

[The statement follows:]

PREPARED STATEMENT OF ARNOLD SCHWARZENEGGER

Mr. Chairman, distinguished members of the audience, and most particularly, Special Olympics athletes and their families, I am grateful and honored to testify before this Committee today. There area two things near and dear to my heart; the importance of physical fitness in creating a healthy lifestyle and Special Olympics. Thanks to your vision and leadership Mr. Chairman, both are the subject of this unprecedented hearing on the health status and needs of individuals with mental retardation.

Thirty-five years ago children born with mental retardation were sentenced to institutions where they were often restrained in beds for days at a time. Parents were told by medical professionals that their child would never learn, could never read, never feed themselves, and never, never would be able to participate in physical activity or exercise.

Yet, one woman with a vision refused to accept these "expert" predictions. In spite of the skeptics, and notwithstanding the stigma and fear that surrounded this population, Eunice Kennedy Shriver instinctively knew that individuals with mental retardation could run and jump and throw a ball and even swim. So she invited them to a camp in her backyard, along with coaches and college students and soon these individuals were running races, riding horses and playing ball. Eunice Shriver's vision extended to the creation of an organization, whose mission statement calls for year-round sports training and athletic competition in a variety of Olympic-type sports for children and adults with mental retardation, giving them continuing opportunities to develop physical fitness. Thus Special Olympics was born, and you can't begin to imagine how far it's come.

Today one million people with mental retardation participate in Special Olympics around the world. This week, nearly 2,000 Special Olympics athletes will compete at these World Winter Games before a global audience. Everywhere I travel, from Southern California, to my homeland of Austria, to China, I see the power of Eunice Shriver's vision. I see athletes competing marathons in less than three hours. I see athletes bowling perfect games. I see Special Olympics athletes speaking out, coaching peers and officiating at world-class events.

Last year Special Olympics athletes joined me as we lit the Flame of Hope at the Great Wall in Beijing. Later, I was joined by athletes at a meeting with President Jiang Zemin where they asked for government support of programs intended to improve the quality of live for people with mental retardation in China; the same country where not long ago, children born with mental retardation were often left to die so parents could have a "normal" baby under the one child per family policy. President Jiang promised to help.

Notwithstanding the life work and vision of my inspirational mother-in-law, the harsh statistics and data contained in this report are sobering. People with mental retardation live an average of 10–20 years less than the general population. Individuals with mental retardation suffer from a wide range of chronic and acute diseases and conditions. In many instances, they experience more frequent and severe symptoms than the general population, including: heart disease, diabetes, obesity, respiratory problems, mental illness, vision deficits, hearing deficits, and oral health problems.

Mr. Chairman, we can and must do something to address the health deficits of people with mental retardation.

We are now at the point where virtually all leaders in the health field, and a large portion of the general public understand that being healthy is more than just not being acutely ill. We understand that regular physical activity reduces the risk of dying from coronary heart disease and of developing high blood pressure, colon cancer, and diabetes. We know that for people with disabling conditions, regular exercise can improve their stamina and muscle strength.

But as much of the American public also knows, establishing and maintaining fitness is no simple, short-term challenge. It is a lifelong requirement for a healthy, productive life. Moreover, despite the increasing focus on personal and general population health promotion and disease prevention, both in the United States and elsewhere, this report points out that persons with mental retardation have received little consideration. In fact, since this population is more likely to encounter secondary health problems, like coronary disease or obesity, it makes sense that health promotion and physical fitness would particularly benefit people with mental retardation.

Therefore, I believe that a broad public health assessment of people with mental retardation needs to be undertaken by leading public health and professional organizations. The new National Center on Birth Defects and Developmental Disabilities at the U.S. Centers for Disease Control and Prevention should have an explicit program focus and adequate resources to fund research and programs on the prevention of secondary disabilities among persons with mental retardation. I also believe that the President's Council on Physical Fitness and Sports, which I had the privilege to chair for President George Bush, should specifically focus on the needs of people with mental retardation. In fact, I call on the new President Bush to appoint a person with mental retardation to his Physical Fitness Council and if he needs any suggestions, I nominate the remarkable Loretta Claiborne seated here next to me.

Sports organizations like Special Olympics should forge ahead too. Too often, lack of appropriate, regular exercise and physical activity regimens, in spite of participation in Special Olympics, leaves many athletes far short of desirable personal physical fitness standards. Accordingly, I am especially pleased that an Athlete Health Promotion Center is being pilot tested at these Special Olympics World Winter Games to teach athletes about wellness and healthy lifestyles. I encourage you to stop by Olympic Town to take a look.

In closing Mr. Chairman, I am ready to help you in any way possible to address the findings contained in this report and to work with you to improve the quality and length of life for people with mental retardation.

Thank you for the opportunity to share my views.

Senator STEVENS. Okay, we will accept that, and I will talk to you about it when we get back to Washington. We ought to be able to follow some of those suggestions, and I thank you very much for taking the time and for being here, and for helping us open these Winter Games.

Mr. SCHWARZENEGGER. Thank you very much.

I think, Mr. Chairman, I have heard all the testimony and I think the bottom line is that Special Olympics has a program, Healthy Athletes, they spend $3 million every year on that. If the Government could come in with just 10 times that amount I think we could make a major move forward.

Thank you very much, Mr. Chairman.

Senator STEVENS. I am afraid you sound like another Kennedy I know.

SPECIAL THANKS TO KIM ELLIOTT

Let me thank the Senior Advisor to the President for Special Olympics, who was very instrumental in making the hearing a reality, and I am sure she is the one who conveyed the request to my son, and he conveyed it to me, so we thank Kim Elliott for what she has done.

CLOSING REMARKS

And we thank all of you for being here. I am going to read the report. It does, I am told, detail what needs to be done to further the health and well-being of individuals with mental retardation, and I think everyone here heard your messages loud and clear.

I will do my best to assure that Congress begins making some decisions concerning the funding recommendations you have made to assist people with mental retardation, and we will do our best to do everything we can to carry out the oath of the Special Olympics.

Again, all of the statements that we have had here will be printed in the record, and we will print all of the testimony. We will make that available to those of you—if you would like to have a copy of the hearing. Send your requests for a copy of the hearing to Tim Shriver at the Special Olympics in Washington, DC.

Thanks to all of you, our very distinguished guests who have joined us today to assist in this hearing, and thanks to all of the Special Olympians who are here. We wish you a wonderful week of Games. I shall not be with you. I have to return to the Senate tonight so we can vote tomorrow, but I will do my best to work with you, and Bettilou and I will talk to some of you about further action as far as our committee is concerned, and thanks to you, Bettilou, for coming up and being a special help in this hearing.

I am going to have two reports inserted in the record at this point: "Promoting Health for Individuals with Mental Retardation—A Critical Journey Barely Begun" and "The Health Status and Needs of Individuals With Mental Retardation."

[The information follows:]

PROMOTING HEALTH FOR PERSONS WITH MENTAL RETARDATION—A CRITICAL JOURNEY BARELY BEGUN

SPECIAL OLYMPICS OVERVIEW

As the largest organization in the world promoting acceptance through sport, Special Olympics has a 32-year track record of demonstrated success in providing year-round sports training and competition opportunities for children and adults with mental retardation. Founded in 1968 by Eunice Kennedy Shriver, Special Olympics, Inc. (SOI) is incorporatedin the District of Columbia as a not-for-profit corporation.

Special Olympics flourishes in 160 nations and in each of the 50 states, the District of Columbia, Puerto Rico, Guam, the Virgin Islands, and American Samoa. One million people with mental retardation annually participate in Special Olympics training and competition programs globally. One million volunteers and 250,000 coaches around the world support these efforts, training athletes in 22 Olympic-type sports and organizing more than 20,000 local, regional, national and international sporting events annually. Through regular sports training programs, Special Olympics athletes enhance their athletic skills, improve their overall physical fitness, and develop increased self-confidence and self-esteem. In fact, published research indicates that for people with mental retardation, regular participation in Special Olympics sports training and competition activities yields all of these benefits and often leads to sustained improvement in overall physical fitness and emotional well-being.[1]

PREVALENCE/CAUSES OF MENTAL RETARDATION

The World Health Organization estimates that there are approximately 170 million people with mental retardation worldwide.[2] In other words, nearly 3 percent of the world's population has some form of mental retardation. Accordingly, mental retardation is 50 times more prevalent than deafness; 28 times more prevalent than neural tube disorders like spina bifida; and 25 times more prevalent than blindness.

A person is diagnosed as having mental retardation based on three generally accepted criteria: intellectual functioning level (IQ) is below 70–75; significant limita-

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[1] Dykens E., Cohen D., *Effects of Special Olympics International on Social Competence in Persons with Mental Retardation.* Journal of the American Academy of Child & Adolescent Psychiatry; 1996; 35.

[2] World Health Organization (WHO): *World Heath Statistics Annuals. Vols. 1990–1996.* Geneva; United Nations. 1997.

tions exist in two or more adaptive skills areas (e.g., communication, self-care, functional academics, home living); and the condition manifests before age 18. Mental retardation can be caused by any condition that impairs development of the brain before birth, during birth, or in childhood years. Genetic abnormalities, malnutrition, premature birth, environmental health hazards, fetal alcohol syndrome, prenatal HIV infection, and physical abnormalities of the brain are just some of the known causes of mental retardation.

NEED TO ASSESS AND RESPOND TO THE HEALTH NEEDS OF INDIVIDUALS WITH MENTAL RETARDATION

A comprehensive report on the status of the health and well being of people with mental retardation worldwide simply does not exist. However, anecdotal evidence, media reports, site visits and limited health data indicate a dire and urgent need to address the health conditions and available health services for this population.

Special Olympics has led the world aggressively where few governments, and certainly not the marketplace, have gone. For more than three decades, Special Olympics has developed and implemented programs in sports training and competition for individuals with mental retardation. The health benefits of sports training and competition for those with mental retardation are widely acknowledged by family members and professionals in the fields of mental retardation, health and sports.

In recent years, Special Olympics has addressed the health needs of its athletes more directly through its Special Olympics Healthy Athletes Program and its Research and Evaluation Initiatives. Special Olympics Healthy Athletes provides health assessment, health education, disease prevention, and in many cases, corrective health care for Special Olympics athletes. While the program is experiencing dramatic growth, it is still limited in terms of the number of persons who can be served.

Special Olympics is exerting leadership in the area of health for persons with mental retardation because, to date, adequate leadership has not emerged from the health care or public policy communities. Moreover, while there has been some welcome progress in terms of increased life expectancy and quality of life for persons with mental retardation over the past several decades, major health gaps remain and health improvement opportunities remain widely under-addressed.

To respond to the dearth of data on the health of people with mental retardation, Special Olympics commissioned a Special Report on the Health Status and Needs of Individuals with Mental Retardation.[3] The purpose of this report is to identify opportunities that may be available, given current scientific knowledge and technology, to improve the quality and length of life for persons with mental retardation, and most notably, Special Olympics athletes.

In one sense, this report is an in-depth, scientifically supported "report card" on the health of persons with mental retardation and the adequacy of programs, systems, and policies, designed to assist those with mental retardation live longer, better, and healthier lives. Specifically, the Health Report identifies the current health status and needs of persons with mental retardation; describes policy and program gaps in health care and physical fitness; and offers recommendations to improve access to and the quality of health care for people with mental retardation.

Renowned researchers Dr. Edward Zigler, Dr. Sarah Horwitz, and colleagues from Yale University undertook an extensive literature review (175 pages, 540 citations, over 1,100 pieces of literature screened), which provides a basis for much of the health report. Dr. Donald Lollar, Associate Director of the Office for Disability and Health at the U.S. Centers for Disease Control and Prevention also assisted with preparation of the report.

GENERAL PUBLIC POLICY BACKDROP

Length and quality of life are central concerns of numerous high-level policy initiatives in many countries, including the United States. The recent launch of the Healthy People 2010[4] initiative marks the third decade of a national commitment to improving the health and general wellbeing of Americans. Major goals of the initiative include increasing the quantity and quality of life and reducing health disparities among various populations. However, if one focuses on the health status, needs and opportunities for persons with disabilities, the public policy record is

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[3] Horwitz, S., Kerker, B., Owens, P., Zigler, E. *The Health Status and Needs of Individuals with Mental Retardation.* Washington, D.C.; Special Olympics, Inc., March 2001.

[4] U.S. Department of Health and Human Services. *Healthy People 2010* (Vol. I) 2nd ed. Washington, D.C.; GPO, November 2000.

much more spartan. The previous Healthy People 2000 initiative,[5] launched by the U.S. Department of Health and Human Services in 1990, included little direct focus on the health status and needs of persons with disabilities.

To its credit, the Healthy People 2010 report dedicates a chapter and a number of "developmental objectives" to persons with disabilities. Yet, the chapter does not specifically address the health status, needs and access issues confronting millions of Americans with mental retardation or other specific disability groups. Further, there are notations of "no available data", "inadequate data", or "unanalyzed data" concerning persons with disabilities throughout the entire document. Similarly, several recent highly visible federal reports addressing oral health challenges and lack of access to oral health services for several special needs populations, barely mentioned the population with disabilities, including individuals with mental retardation.[6]

Healthy People 2010 outlines a vision for access to health care for every U.S. citizen:

". . . the principle—that regardless of age gender, race, ethnicity, income, education, geographic location, *disability* (emphasis added), and sexual orientation—every person in every community across the Nation deserves equal access to comprehensive, culturally competent, community-based health care systems that are committed to serving the needs of individuals and promoting community health."

Unfortunately, achieving this goal remains a major challenge, especially for individuals with mental retardation in the United States and elsewhere.

MAJOR FINDINGS

The major findings, conclusions and recommendations contained herein are drawn from several sources, including: an independent, comprehensive review of the literature undertaken by scholars at Yale University, learned opinions from health and disability experts from various countries; administrative data derived from Special Olympics programs; and direct experiences of Special Olympics athletes, their families, program staff, and volunteers. Consistent with policies of Special Olympics, the findings, conclusions and recommendations in this report have been shared with and reviewed by a number of Special Olympics athletes.

1. Individuals with mental retardation suffer from a wide range of chronic and acute diseases and conditions. In many instances, they experience more frequent and severe symptoms than the general population. This is not solely a result of the primary disability of mental retardation, but reflects more fully the totality of risk factors and risk reduction opportunities made available to or denied to them.

Importantly, their life and health experiences can not be adequately explained or rationalized solely by the fact that they have mental retardation, since they are impacted by secondary conditions and persisting environmental factors (social, economic, physical, etc.) that fail to ameliorate, or in some cases actually exacerbate their risks.

2. Evaluating isolated categorical health deficits or conditions in persons with mental retardation through simple disease/condition comparisons with the general population is not, in itself, adequate for assessing health status or the need for health improvement. Even where there is evidence that the prevalence of a specific disease or condition may be similar between the general population and those with mental retardation, the adverse impacts can be greater on those with mental retardation. Health must be seen in overall functional terms, especially for populations with disabilities.

3. Numerous measures indicate that persons with mental retardation experience lower life expectancy and lower quality of life than the population in general. The magnitude of these gaps can not be explained solely by the existence of the mental retardation condition.

4. Notwithstanding the increasing focus on personal and population health promotion and disease prevention, both in the United States and elsewhere, persons

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[5] U.S. Department of Health and Human Services. *Healthy People 2000*. Washington, D.C.; GPO, January 1990.

[6] U.S. Department of Health and Human Services. *Oral Health in America: A Report of the Surgeon General*. Rockville, Maryland. U.S. Department of Health and Human Services, National Institute of Dental and Craniofacial Research, National Institutes of Health, 2000.

U.S. General Accounting Office. *Oral Health—Dental Disease Is a Chronic Problem Among Low-Income Populations* (Rep #HEHS–00–72). GAO; Washington, D.C., April 2000. U.S. General Accounting Office.

Oral Health—Factors Contributing to Low Use of Dental Services by Low-Income Populations. (Rep #HHES–00–149). GAO; Washington, D.C., September 2000.

with mental retardation have received little consideration. Consistent with this finding, the information concerning the health status and needs of persons with mental retardation is entirely inadequate. Further, there is a scarcity of information on specific disease prevention and health promotion interventions that could improve the quality and length of life for persons with mental retardation.

5. Even in situations where persons with mental retardation experience similar levels of disease to persons without mental retardation, access to timely and appropriate health care often is not adequate and generally poorer than for the overall population. This leads to unnecessary suffering, functional compromise, and costs to individuals, families and society.

6. Although persons with mental retardation need health and health financing programs that are responsive to their particular needs, too often they are forced into general programs that actually can compromise their health. The most recent example of this is the movement toward managed care in Medicaid.

Families have served as principal advocates for the health care of their children with mental retardation. While many families are fortunate to have private health insurance and/or personal resources to help cover health care expenses, too many families and individuals face substantial health care costs on their own. While a large percentage of the population with mental retardation is covered under state Medicaid programs, many of these programs are plagued by a variety of problems, including poor reimbursement rates to providers, excessive paperwork and delays, limitations and exclusions in benefits, and a generally poor reputation among providers.

As an example, while dental services for many children are covered under Medicaid, only one-in-five eligible children receives any dental services each year.[7] In most states, there are limited dental care benefits for adults, so that individuals with mental retardation are no longer eligible for dental care coverage under Medicaid, once they reach the age of maturity. Also, it should be noted that dental care is essentially unavailable under Medicare.

7. The majority of health professionals, who are otherwise qualified to treat persons with mental retardation, fail to do so. This is largely the result of a lack of appropriate, specific training, inadequate reimbursement policies, fear, and prejudice.

8. Existing federal, state and voluntary programs to meet the health needs of persons with mental retardation are inadequate. Enhanced and new efforts with supplemented and targeted resources will be required. Coordinated and integrated, not piecemeal, efforts must be a priority.

9. Significant additional targeted research is needed to more fully characterize and understand the health status and needs of persons with mental retardation and to test models for improving health. Still, existing data are adequate to conclude that persons with mental retardation are woefully under-addressed in terms of national (virtually every nation's) health priorities. The Special Olympics Strategic Research Plan[8] can serve as a blueprint for many research efforts. However, strong research partners, including funders, will be necessary.

RECOMMENDATIONS

1. All public and private programs, initiatives and reports that address the health needs of the general public should explicitly examine the unique needs of persons with mental retardation.

Because of the complex constellation of physical, mental, and social variables that combine to challenge the health and wellbeing of this population, general conclusions based on individual demographic or risk factors are inadequate for designing effective policies and programs to help persons with mental retardation. "One size fits all" solutions to the financing and delivery of services will assure that persons with mental retardation will continue to be under-served and/or receive inappropriate services.

2. An expert working group should be convened by the Secretary of the U.S. Department of Health and Human Services to address equity gaps and opportunities that exist to better characterize the health needs of persons with mental retardation. If necessary to stimulate action, public hearings should be convened by Congress to garner necessary focus and priority.

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[7] U.S. Department of Health and Human Services. Office of Inspector General. Children's Dental Services Under Medicaid—Access and Utilization. San Francisco; Office of Evaluations and Inspections, April 1996.

[8] Special Olympics, Inc. *Strategic Research Symposium Papers.* Pittsboro, North Carolina, June 24–25, 1999.

The goals of the Healthy People 2010 initiative only can be achieved when the health status and needs of specific populations are well documented, effective community and clinical education programs exist, prevention and treatment programs are designed, and adequate resources are made available.

3. The Inspector General of the U.S. Department of Health and Human Services, as well as the Association of State Attorneys General, should evaluate whether the provisions of publicly funded and private health programs are providing equal or equitable protection to persons with disabilities, including those with mental retardation.

The Yale University literature review points out that the health care system in the United States, and those in many other nations, are often characterized by negligence, indifference and blatant discrimination against people with mental retardation. This issue must be addressed in the context of civil rights.

4. Specific health objectives for persons with mental retardation should be established, consistent with the overall goals of Healthy People 2010—namely, "to increase quality life years and to reduce the gaps in health status." Public schools are provided with a great opportunity to improve the health of school-aged individuals with mental retardation. By law, public schools are required to provide an Individualized Education Program (IEP) for every child with mental retardation. As part of each IEP, the health needs of children with mental retardation should be assessed and appropriate services accessed.

Leadership should come from the U.S. Department of Health and Human Services through the Administration on Developmental Disabilities, Centers for Disease Control and Prevention (CDC) and the National Institutes of Health (NIH), in conjunction with the U.S. Department of Education.

5. The CDC should conduct a comprehensive review of the degree to which data collection and analysis regarding the health and wellbeing of persons with mental retardation have positively or negatively impacted the lives of persons with mental retardation and what opportunities exist to redress past shortcomings.

Substantially enhanced documentation of the health status and needs of persons with mental retardation is needed. Currently, too many surveillance processes fail to collect adequate information on this population and fail to perform relevant data analyses in a timely fashion, which then could inform policy development and program design.

6. A focused effort to create health literacy enhancement opportunities for persons with mental retardation needs to be undertaken.

Closing the gap in health literacy has been identified in the Healthy People 2010 initiative as a principal strategy for reducing health disparities. Persons with mental retardation also need to have health information presented to them in ways that may empower and motivate them toward seeking higher levels of health. While this will not be possible universally, there are tens of millions of persons with mental retardation globally who can not simply be categorized as unable of taking an active role in their own healthcare. Further, caretakers will be more motivated to act in the best health interests of persons with mental retardation if they are aware of what appropriate standards are.

7. A broad public health assessment of mental retardation needs to be undertaken by leading public health and professional organizations that can lead to the formulation of effective organizational policies and programs. The new National Center on Birth Defects and Developmental Disabilities at CDC should have an explicit program focus and adequate resources to fund research, surveillance, and assessments on the prevention of secondary disabilities among persons with mental retardation.

The public health community needs to reassess and reprioritize mental retardation as an important public health challenge that goes beyond simply primary prevention of diseases and conditions that result in mental retardation.

8. The NIH and other federal agencies with a health research mission should allocate increased levels of funding to issues critical to understanding all dimensions of mental retardation, and where research opportunities exist, to pursue the prevention and rectification of the primary and secondary effects of mental retardation.

Special Olympics should formally transmit its strategic research agenda to these agencies as a basis for consensus development around the strategic role of federal agencies in such research.

9. Special Olympics should convene a blue ribbon corporate health advisory group to develop a strategic and integrated corporate strategy for maximizing the impact of corporate contributions (intellectual, technical assistance, in-kind, cash) for the betterment of persons with mental retardation.

Given the inadequate resources and attention to the health needs and possibilities for persons with mental retardation, it is time for leading health advocacy organizations, including pharmaceutical companies, health equipment and supply companies,

health insurers, and government and philanthropic organizations to commit resources to promoting health and preventing disease in this population, so that by 2010, clear health gains and realistic health promotion opportunities are created for persons with mental retardation.

Likewise, leading philanthropic organizations need to undertake a critical self-examination of the degree to which they have addressed the health needs of persons with mental retardation. Organizations with weak records of support in this area should make concrete commitments to funding programs and projects to improve the health of persons with mental retardation.

ADDITIONAL GLOBAL PERSPECTIVES

The findings and recommendations contained herein, have as their principal basis the comprehensive literature review conducted by Horwitz et. al. at Yale University, data and perspectives from Special Olympics Programs, and responses from key informants from a number of countries who are knowledgeable of, and work in, areas related to mental retardation.

Dr. Stephen Corbin and Dr. Donald Lollar asked professional colleagues in several countries to respond to a survey instrument (available from Special Olympics upon request) containing items addressing the existence of data, policies, laws, and programs for individuals with mental retardation. The key informant responses were solicited after completion of the other portions of the report so that they might serve a validation function. Responses came from individuals in Kenya, India, Australia, and the Czech Republic. These responses did indeed validate the findings and recommendations that had been articulated in the Yale University literature review.

To date, health data collection and analysis for the population with mental retardation has not been a priority in these countries. Representative country data were not available to characterize the health status and needs of persons with mental retardation in any comprehensive way. Data that are available are not collected on an ongoing or periodic, scheduled basis. The tendency is for official data collection sources to seek data on disability in general or to rely on general population data which are of limited utility for understanding the health needs of persons with mental retardation.

Some institutional data are available (Czech Republic), but the depth of information varies significantly. It was noted that in Australia, de-institutionalization of persons with mental retardation has interrupted not only the availability of health services to these persons, but also negatively impacted the collection of information about the health needs and health service access for much of this population.

All respondents indicated that access to necessary health care services for individuals with mental retardation is a problem. Even in countries where medical care is made available by law to all citizens, persons with mental retardation have difficulty receiving needed care from qualified providers. Children with mental retardation tend to fare better than do adults with mental retardation. Those living in cities generally receive inadequate care and those in villages are even worse off. Non-Governmental Organizations (NGOs) provide some assistance (Kenya), but this is not sufficient. It was pointed out that in Australia, many conditions could be ameliorated and/or prevented by early intervention, but periodic screening is not a well-established part of the system. Disease prevention and health promotion services for persons with mental retardation do not appear in any systematic way through government or private sources and are not a public priority.

Further, bias against persons with mental retardation is reported to exist still, even among health care providers, and most persons with mental retardation are not in a strong position to communicate their health needs and desires. Several respondents indicated that individuals with mental retardation may be eligible for a level of services similar to those provided to individuals with other disabilities, but in actuality, they usually end up with poorer access to care. For example, in India, individuals with visual impairments and individuals who are orthopedically challenged have better access to health services than do individuals with mental retardation. Lack of adequate resources to pay for needed care is a consistent problem and, in the case of institutions (Czech Republic), adequate resources to provide appropriate staffing levels is a challenge.

The greatest barriers to the improvement in health status for persons with mental retardation include negative attitudes among the public, governments, service providers, and, in some instances, even among family members. The health needs of persons with mental retardation do not register high enough on the priority scale to attract the resources and attention that they merit. Even where policies and laws exist that should provide a basis for needed services for persons with mental retardation, there is little attention to surveillance and enforcement.

Informants made a number of suggestions about the most important actions that could be taken over the next decade in order to increase life expectancy and quality of life for persons with mental retardation. These include:

—Earlier, more adequate and more frequent health screening;
—A more responsive general health system;
—Additional training and strong encouragement for health professionals to meet the needs of people with mental retardation;
—The development of a network of specialized tertiary referral health clinics to support the general health services and to provide a base for research and training;
—Adequate national data bases;
—Implementation of existing laws;
—Implementation of a mass market public awareness program through print and electronic media, including the internet, to better sensitize the public as to the nature and needs of persons with mental retardation;
—A stabile health insurance system with adequate financing;
—Standardized, periodic screening targeting prevention and needed care;
—Better communication about the lives of persons with mental retardation, coupled with training in communications and ethics for care providers;
—Governments that recognize mental retardation as a health care specialty and subsequently enact policies favorable to people with mental retardation; and,
—Support of National Special Olympics Programs through which governments, the general public, professionals, and organizations can assist in health promotion and disease prevention efforts on behalf of persons with mental retardation.

SPECIAL OLYMPICS HEALTHY ATHLETES—AN INITIAL APPROACH TO ADDRESSING THE HEALTH NEEDS OF PERSONS WITH MENTAL RETARDATION

Special Olympics has provided year round sports training and competition opportunities for persons with mental retardation for more than three decades. Over a million athletes of all ages participate in a variety of summer and winter Olympic-type sports.

Special Olympics was started by Eunice Kennedy Shriver in 1968 because persons with mental retardation consistently were excluded from societal opportunities, including sports and recreation. She recognized that persons with mental retardation could accomplish significant things through sport, while, at the same time, finding meaning in their lives. Since that time, the public record of service and opportunity provided to persons with mental retardation through Special Olympics has been documented through extensive print and electronic media and a continuing stream of highly visible public events.

In recent years, Special Olympics has expanded its interest in the health of its athletes by supporting research activities, organizing medical symposia, and collaborating with international organizations on prevention issues.

Beginning in 1989, the health needs of persons with mental retardation were highlighted as a result of vision screening clinics initiated through the Sports Vision Section of the American Optometric Association. These initial clinics demonstrated that Special Olympics athletes had significant and highly prevalent vision impairments and that they were woefully lacking in quality vision care opportunities.

In the early 1990s, an additional program, Special Olympics Special Smiles, was created to address the unmet oral health needs of Special Olympics athletes. Like Special Olympics Opening Eyes, Special Olympics Special Smiles demonstrated that Special Olympics athletes had a significant unmet need for oral health care. Boston University's Goldman School of Graduate Dentistry provided the founding institutional home for Special Smiles and enabled the program to grow quickly.

WHAT IS SPECIAL OLYMPICS HEALTHY ATHLETES?

Special Olympics Healthy Athletes is a diverse program of health assessment, professional training, service provision, and health referral services for Special Olympics athletes. Special Olympics Healthy Athletes screening clinics are conducted in conjunction with sports competitions at local, state, national, regional, and global levels. These programs are elective for Special Olympics Programs and Games Organizing Committees. Despite the non-mandatory aspect, Special Olympics Healthy Athletes programs have been expanding rapidly, based on the recognition that they provide a new and valuable range of services and resources to Special Olympics athletes. Special Olympics Healthy Athletes is not intended to be a comprehensive health care system, but rather is a short-term, limited, yet practical means for

bringing a range of health services to Special Olympics athletes in a welcoming, respectful, and non-discriminatory setting.

Special Olympics Healthy Athletes programming includes:

—Delivery of direct health care services to Special Olympics athletes;
—Health education services for athletes;
—Athlete referral for needed follow-up health care;
—Documentation of the health status and needs of athletes;
—Recruitment and training of health personnel in treating people with mental retardation;
—Advocacy for improved public policies in support of the health needs of people with mental retardation; and,
—Advancing knowledge about the delivery of health care to persons with mental retardation.

RANGE OF SERVICES PROVIDED

The Special Olympics Healthy Athletes program components offer the following range of health care services, varying by discipline and specific screening protocols:

—Screening assessment;
—Clinical examination;
—Health education/counseling;
—Preventive services;
—Corrective services;
—Personal preventive supplies;
—Referral for follow-up care; and,
—Interaction between athletes and specially trained and motivated health care providers.

Qualified experts from the health disciplines within the Special Olympics Healthy Athletes program determine the appropriate contents and standards for their screening and service offerings, based on the state of science and clinical practice, with adaptations for the special population that is being served. Special Olympics Program leaders along with the Special Olympics Global Medical Advisory Committee and legal staff monitor and approve overall program scope and practices.

In 2001, more than 100 Special Olympics Healthy Athletes screening clinics will be conducted. This includes screening events at local, state, national, and international levels. Also, beginning in 1999, several additional health disciplines were pilot tested for the first time as Special Olympics Healthy Athletes components. They include: hearing; physical therapy; dermatology; and orthopedics. Screening clinics in these disciplines have been conducted at a number of Games in the U.S. and abroad, and further growth in these and other medical disciplines is anticipated.

SPECIAL OLYMPICS HEALTHY ATHLETES PROGRAM FINDINGS

In addition to the health services that Special Olympics athletes receive through the Special Olympics Healthy Athletes program, valuable insights have been gained as to the health status and needs for this population. As reflected in the Yale University literature review, Healthy People 2010, and feedback by key informants from different countries, there is a general lack of information as to the health status and needs of persons with mental retardation. Further, available data generally are from small institutionally based studies or from the administrative records of public agencies.

Specific advantages of the data derived from Special Olympics Programs is that the population served is substantial and includes athletes of all ages from around the world. Literally tens of thousands of Special Olympics athletes have been screened through the Healthy Athletes program to date. Further, the data have been collected using standardized protocols developed by experts in the field (e.g., U.S. Centers for Disease Control and Prevention).

Limitations in the data that must be recognized include the large number of examiners involved, the limited sensitivity of the survey instrument in some cases to detect quantitative differences in levels of disease (e.g., oral health screening instrument), and the convenience aspects of the population being reported on (e.g., athletes participating in Special Olympics events may not be fully representative of the larger community of institutionalized and non-institutionalized persons with mental retardation worldwide.

As pointed out in the Yale University literature review, there appear to be certain health advantages or disadvantages based on an individual's residential status. A number of disease conditions may be more prevalent among individuals with milder retardation living in freer environments where they must make conscious choices

to avoid health risks (e.g. tobacco use) or to practice healthy habits on their own (e.g. oral hygiene, physical exercise, etc.). Nevertheless, there is little doubt that that Special Olympics Healthy Athletes data make a valuable contribution toward understanding the health status and needs of persons with mental retardation and planning programs and policies to address unmet needs.

VISION HEALTH OF SPECIAL OLYMPICS ATHLETES

Nearly 10,000 athletes have received vision assessments through Special Olympics Opening Eyes program since its inception. It is anticipated that in 2001, due to program expansion facilitated by a major, multi-year grant from the Lions Clubs International Foundation, an additional 6,000–7,000 athletes will directly receive such screenings.

Findings have been fairly consistent over several years of assessments. Special Olympics athletes had not received adequate vision care in terms of timeliness and many require corrective services. Over 60 percent had not received a vision assessment in the past three years. Between one-fifth and one-third of athletes required glasses for the first time or replacement glasses. In many instances, athletes were wearing prescriptions that were found to be grossly inaccurate. The prevalence of astigmatism (44.2 percent) and strabismus (17.8 percent) were high. A high percentage of athletes examined would be classified as legally blind according to World Health Organization criteria.

Many anecdotal reports identified athletes who, after receiving eyewear through the Special Olympics Opening Eyes program, could, for the first time, see the finish line and their friends and families cheering for them. In a number of instances, coaches and family members reported that the new eyewear literally changed the personality of individual athletes and immediately enhanced their quality of life, while reducing certain risks (e.g. injury from falls or collisions). Additionally, many athletes received prescription swim goggles and prescription or plano safety sports glasses intended to prevent sports injuries.

ORAL HEALTH OF SPECIAL OLYMPICS ATHLETES

Oral health assessments have been provided to approximately 20,000 athletes through the Special Olympics Special Smiles program over the past seven years. Most screening clinics have been conducted in the United States, although it is anticipated that major program growth, starting in 2001, will take place outside the United States.

Special Olympics Special Smiles utilizes an assessment instrument developed by the CDC especially for Special Olympics. The instrument was designed to be reliable when used by a variety of trained examiners under varying conditions. This comes at the expense of providing elaborate quantitative detail. For example, an athlete might be assessed for obvious dental decay in at least one tooth. If such were the case, the assessment form would be marked "yes." However, if several teeth for an athlete had obvious decay, the "yes" category likewise would be marked. Thus, there is no apparent distinction when examining data as to the extent of dental disease in an individual athlete. This protocol differs from more sophisticated epidemiological studies conducted periodically by federal and state governments, which precisely quantify the presence of dental disease down to relatively small caries lesions on individual tooth surfaces. The limitations of government studies, however, is that they fail to include an adequate number of individuals with mental retardation to provide meaningful results or they fail to identify individuals by disability category.

Notwithstanding the limitations in the data derived from the Special Olympics Special Smiles screenings, a good overall picture emerges of the oral health status and needs of Special Olympics athletes. The 1999 Special Olympics World Summer Games in Raleigh, North Carolina are representative. For the over 2,200 athletes of all ages examined, nearly 20 percent reported pain in the oral cavity, the vast majority attributed to tooth pain. Much untreated dental decay exists in Special Olympics athletes. Nearly one-in-three had active dental decay (untreated) in molar teeth and more than one-in-ten had active decay in pre-molar or anterior (front) teeth. Fewer than one-in-ten of the athletes screened had preventive dental sealants present on any molar teeth.

There is a clear need for more professional dental care to be made available to this population. More than 40 percent of screened athletes were in need of professional care beyond the level of routine, maintenance care; more than one-third of these needed urgent care. There were substantial differences between U.S. and non-U.S. athletes in terms of the oral health care needed. Nearly half of non-U.S. athletes were in need of care beyond routine maintenance care compared to 28.4 per-

cent of U.S. athletes. Urgent care was required nearly three times as often (19.9 percent) for non-U.S. athletes as for U.S. athletes (7.1 percent).

During 2000, 35 Special Olympics Special Smiles screening clinics were conducted, serving nearly 10,000 athletes. While the results from site to site demonstrated some variations in individual measurement categories, overall the data were consistent with the data gathered at the 1999 Special Olympics World Summer Games.

HEARING HEALTH OF SPECIAL OLYMPICS ATHLETES

The Special Olympics Healthy Hearing program is much newer than the Special Olympics Opening Eyes or Special Smiles programs. The first hearing screening was conducted as part of the Special Olympics World Summer Games in 1999. A second large-scale event was conducted at the 2000 Special Olympics European Games in Groningen, the Netherlands.

During the European Games, 529 athletes were screened at the Special Olympics Healthy Hearing venue. The athletes were from 61 countries. Screenings included otoscopic examination of external ear canals, otoacoustic emissions (OAE) hearing tests, pure tone audiometry, and tympanometry to screen middle ear function. Twenty-six percent (26 percent) of the athletes failed the hearing screening as compared to a general population rate expected to be less than 5 percent. Of this group, 52 percent did not pass tympanometric screening, suggesting the presence of a conductive (probably medically correctable) hearing loss. Conversely, 48 percent passed the tympanometric screen, which implies that they failed the hearing screening due to a sensorineural (permanent) hearing loss.

Of the nearly three-quarters of the screened athletes who passed the screening protocol, one-in-five had ear canals blocked or partially blocked with cerumen (ear wax), reflecting a lack of ear hygiene and professional care. The results from the Groningen screening were similar to those compiled at the 1999 Special Olympics World Summer Games.

OBESITY AS A RISK FACTOR FOR SPECIAL OLYMPICS ATHLETES

According to Healthy People 2010, the prevalence of overweight individuals is on the rise with 11 percent of school age children and 23 percent of adults being classified as obese. The prevalence of obesity in the population with mental retardation has been reported as more common than in the general population. Obesity has been implicated as a major preventable health risk factor for the general population. These risks include a higher prevalence of cardiovascular disease, cerebrovascular disease, diabetes mellitus, and certain types of cancer.

In 1999, during the Special Olympics World Summer Games, nutritional assessment and education were included in the Healthy Athletes program for the first time. Adding this assessment to the Healthy Athletes clinics was a response to the increasing focus on the nutritional status among the general population. For Special Olympics athletes who train and enter athletic competition, being under-weight or over-weight, (representing poor nutritional status in both cases) may affect general wellbeing and performance. One thousand and sixty-six (1,066) Special Olympic athletes were assessed by anthropometric measurements. These included height and weight used to calculate a Body Mass Index (BMI) which equals weight (Kg)/ht (m^2)) for each athlete. There were 421 athletes from the United States and 645 from other areas of the world.

The BMI measurements were standardized for age using the NHANES III BMI values. BMI values for children and adults have been standardized in the U.S. for the general population, but presently there are no available established BMI values for children and adults with mental retardation. Each athlete who volunteered was evaluated anthropometrically by obtaining height and weight. BMI percentile ranges across ages were then compared. BMI below the 5th percentile represented malnutrition and between the 5th and 15th percentile a risk of under nutrition. BMI greater than 85th percentile represented obesity and greater than 95th super obesity with significant health risk factors.

For U.S. athletes, 3.3 percent were below the 5th percentile compared to 5.2 percent of athletes from other countries. The 5th to 15th percentile included 5 percent of U.S. athletes and 7.1 percent of athletes from other countries. There were 11.2 percent of U.S. athletes between the 15th and 50th percentile and 30.9 percent from other countries. For the 50th to 85th percentiles, there were 27.6 percent of athletes from the U.S. and 36.6 percent of other athletes. Fifty three percent (53 percent) of U.S. athletes and 20 percent of athletes from other countries were greater than the 85th percentile BMI, with 33 percent of American athletes and 7 percent of athletes from other countries greater than 95th percentile.

These findings reflect that the majority of U.S. athletes competing at the 1999 Special Olympics World Summer Games were above the 85th percentile and thus, were obese. Further, 33 percent would be considered in a group with significant health risks because of super obesity. More data for specific age, sex, living conditions and diagnoses for nutritional status in the population with mental retardation need to be obtained. Also, the percentage of patients with Down syndrome relative to the general population with mental retardation is generally thought to be more obese and may need to be studied separately.

Thus, it is apparent that increased efforts to work with athletes, coaches, families, teachers, health care providers, and program administrators in the area of diet, nutrition, weight control, and fitness are needed.

Training Health Professionals to Treat Persons With Mental Retardation

It stands to reason that for individuals with mental retardation to have their health needs met, there must be trained, willing health care providers available to do so. As reflected in the Yale University literature review, a number of reports indicate that health care providers overall feel ill prepared and minimally motivated to treat persons with mental retardation, even for conditions found routinely in the general patient population. Health professional students receive little didactic exposure to the health needs of persons with mental retardation during their training and even fewer have meaningful clinical experiences with such patients.

Accordingly, Special Olympics has made it a priority to train health professional volunteers and to provide them with hands-on experience in serving persons with mental retardation. Typically, health professional volunteers for the Special Olympics Healthy Athletes program receive didactic training as to the nature of mental retardation, special health and social challenges faced by persons with mental retardation, special aspects of their own discipline relating to mental retardation, and effective techniques for rendering quality clinical services to this population. Volunteers additionally receive actual experience, lasting from several hours to several days, depending on the nature of the event, to provide service to, and interact with, Special Olympics athletes. They are accorded continuing professional education credit for this experience.

Consistently, health professional volunteers report their Special Olympics Healthy Athletes experience in extremely positive terms. Many individuals characterize the experience as the most meaningful professional encounter of their careers. Students typically become highly motivated to seek additional experience with special needs populations. Research conducted by Special Olympics clinical consultants on health professional volunteers indicates that volunteer optometrists have a reasonably high expectation for the capabilities of persons with mental retardation prior to their Special Olympics Healthy Athletes experience, and, that after their experience, they report even more positively in terms of what persons with mental retardation can accomplish in life and contribute to society. Oral health providers (dentists, dental students, dental hygienists) evaluated using the same instrument showed similar, albeit less consistent, results.

Legacy of Care

While the health services provided to Special Olympics athletes in conjunction with Special Olympics Games are valuable in their own right, they are minimal in the context of the overall health needs of persons with mental retardation on a year round basis.

The ultimate goal of the Special Olympics Healthy Athletes program is to create a legacy of care for persons with mental retardation. The practicality of such a goal will only be apparent after additional research is conducted to determine whether, in addition to improved health professional attitudes, active commitments to outreach and the care of persons with mental retardation can be realized in providers' home clinics, hospitals and practices. Another important question is whether health professionals who have had such experiences subsequently reach out and encourage colleagues to become providers of care to persons with mental retardation. Only when this happens to a significant degree, will the goals espoused in Healthy People 2010 be achieved for all people.

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Appreciation is extended to the following individuals who reviewed and provided comment on this report during its development:

Francis Dashnaw, Special Olympics Coach and Parent of a Special Olympics Athlete, Fredericksburg, Virginia; Francis Dashnaw, Jr., Special Olympics Athlete, and Employee, Special Olympics, Inc., Washington, D.C.; Renee Dease, Special Olympics Athlete, and Employee Special Olympics, Inc., Washington, D.C.; Robert Jones, Special Olympics Athlete, and Employee Special Olympics, Inc., Washington, D.C.; Marty Wyngaarden Krauss, Ph.D., Professor of Social Welfare & Director, Starr Center for Mental Retardation, Brandeis University, and Special Olympics Board Member, Waltham, Massachusetts; The Honorable Rosario Marin, Councilwoman, City of Huntington Park, and Special Olympics Board Member, Huntington Park, California; Mehmet Oz, M.D., Cardiologist, and Irving Assistant Professor of Surgery, Columbia University, New York, New York; Courtney Pastorfield, Manager, Special Olympics Healthy Athletes, Special Olympics, Inc., Washington, D.C.; The Honorable Sargent Shriver, Chairman, Special Olympics, Inc., Washington, D.C.; Joanne Simons, President, National Down Syndrome Congress, Redding, Massachusetts; The Honorable Sue Swenson, Commissioner, Administration on Developmental Disabilities, U.S. Department of Health and Human Services, Washington, D.C.; Joseph B. Warsaw, M.D., Dean, College of Medicine, University of Vermont, Burlington, Vermont.

THE HEALTH STATUS AND NEEDS OF INDIVIDUALS WITH MENTAL RETARDATION

CHAPTER 1.—INTRODUCTION

PURPOSE

In recognition of the need to improve the quality of life of individuals with mental retardation (MR), Special Olympics Inc. (SOI) commissioned this report to examine the health needs of children and adults with MR. The purpose of this report is

three-fold: (1) to identify the current health status and needs of individuals with MR, (2) to identify services gaps in supporting these needs and (3) to propose specific recommendations to address the unmet health care needs of individuals with MR.

Early in the 20th century, individuals with MR were generally isolated, rather than encouraged to lead fulfilling and healthy lives (David, 1970; Rix, 1986, Campbell, 1999). The last 40 years, however, have seen dramatic changes in sentiments regarding those with MR, resulting in a turn in public policy towards an emphasis on normalization and inclusion (Rowitz, 1992; Kauffman and Hallahan, 1995; Parmenter, 1999). Other developed countries, such as Canada, the United Kingdom (U.K.), the Scandinavian countries and Australia, have seen similar movements (Malin, 1981; Rowitz, 1990; Parmenter, 1999).

As a result of these changes in developed countries, much debate and research has focused on the prevention of MR, deinstitutionalization, and the education and employment of individuals with MR (Tizard, 1971; Clarke, 1991; Anderson et al., 1998). In the U.S., these themes are reflected in court cases, legislative actions and federal initiatives, including Wyatt v. Stickney (1972), Public Law 94–142 and its successor, the Individuals with Disabilities Education Act (IDEA), the Americans with Disabilities Act (1990) and reports by the President's Committee on Mental Retardation (Anderson et al., 1998). Globally, a variety of international organizations, such as the International Association of Scientific Studies on Intellectual Disability, have been developed to support and study both the prevention of MR and the public education concerning individuals with MR (Clarke, 1991). The health status and health service needs of individuals with MR, however, have received little attention over the past four decades.

This lack of attention to health status is surprising, particularly in light of the tremendous gains in life expectancy which have resulted from medical and public health advances. The life expectancy of individuals in the U.S. increased 27.26 years between 1900 and 1990 (NCHS, 1999), and in 1997, the average life expectancy was 76.5 years (Anderson, 1999). Similarly, the life expectancy for individuals in Western Europe increased in the past century, resulting in a current average life expectancy of 74.0 years (Population Division, 1998). Increased longevity is evident not only in the general population, but also among individuals with MR (Rowitz, 1992; Janicki and Breitenbach, 2000). Currently, the average life expectancy of older adults with MR is 66.1 years, but younger adults with MR are expected to live as long as their peers without MR (Janicki et al., 1999). With improved assistive technology and effective public health programs that control most infectious diseases, not only are individuals with mild MR living longer but some individuals with more severe MR also have increased life expectancies (Eyman et al., 1988). As a result, these individuals have recently been faced with the same chronic diseases, including cardiovascular disease, cancer and diabetes, which confront the general adult population (Moss and Turner, 1995 in Barr et al., 1999).

Although effective health prevention strategies and treatments exist for many diseases (Bunker et al., 1995; U.S. Preventive Services Task Force, 1996), not everyone benefits equally from these medical interventions. The poor, minorities and the socially disadvantaged disproportionately have poor health outcomes and lack access to adequate health care services (Hertzman et al, 1994). Individuals with MR are particularly vulnerable to having unmet health care needs, as they are faced with many challenges in understanding and maintaining their health (President's Committee on Mental Retardation, 1999). Individuals with MR may have difficulties understanding the effects of behavior on health, the risks and benefits of medical treatment, and the process of accessing appropriate and necessary health services (Barr et al, 1999; President's Committee on Mental Retardation, 1999). In addition, when health care services are utilized by this population, health providers may have difficulties recognizing and treating various diseases, obtaining accurate medical histories and communicating with patients who have cognitive and language disabilities (Schor et al., 1981; Minihan and Dean, 1990; Lennox et al., 1997)

The lack of access to appropriate health care services also may be a relatively new problem for individuals with MR, resulting, at least in part, from the deinstitutionalization of the 1970s and 1980s. Between 1967 and 1997, as individuals with MR were mainstreamed into the community, there was a 71 percent reduction in the number of individuals in state MR/developmental disability facilities (Anderson et al., 1998). Trends of declining populations in MR facilities also are evident in other developed countries, such as Great Britain, where there was a 36 percent reduction in the number of individuals in long-stay hospitals between 1980 and 1990 (Hart, 1998). As a result of deinstitutionalization, all but the most severely disabled individuals with MR are expected to function in the community environment. Many of these individuals can and do achieve levels of functioning that were not pre-

viously thought possible (President's Committee on Mental Retardation, 1999). Not all, however, have their health care needs adequately addressed in the community, due to a limited availability of community resources and a lack of access to both knowledgeable care providers and a continuity of care (Savino et al., 1973; Saenger et al., 1979; Newacheck et al., 2000). In addition, the recent increase in managed care, and its emphasis on cost-containment, may exaggerate the impact that poor access to quality medical care has on this population (Kastner, 1991; Department of Health, 1995 in Jones and Kerr, 1997, President's Committee on Mental Retardation, 1999). As a result, unmet health care needs may be an unintended consequence of deinstitutionalization. Although controversy remains regarding the quality of care received in institutions (Landesman and Butterfield, 1987; Lowe et al., 1995), individuals in residential centers were at least likely to have a usual source of care and be seen by providers experienced in the treatment of individuals with MR (Durkin, 1996).

Consequently, to develop a coherent set of recommendations for the improvement of the health of individuals with MR, a thorough review of the literature on the current health status of those with MR was commissioned by SOI. In preparation for this report, several steps were taken to ensure a thorough review of academic and public policy documents. Researchers searched Medline and PsycInfo for peer-reviewed articles on the physical, mental, dental and ocular health of people with MR, as well as the availability and accessibility of health care services for these individuals. Many of these studies utilized administrative data accessed from service delivery databases. In addition, publications and reports were obtained from national and international organizations focusing on MR, including the American Association for Mental Retardation (AAMR), The Arc of the United States, and the International Association for the Scientific Study of the Intellectual Disabilities (IASSID). Based on a search of GPO Access and the Internet, government documents that relate to the health and health service use of individuals with MR also were obtained. Further, individuals from several federal agencies (including the Centers for Disease Control and Prevention, the National Council on Disability, the President's Committee on Mental Retardation, the U.S. Bureau of Census and the U.S. Department of Health and Human Services) were contacted and interviewed. Although numerous articles exist regarding the health status and needs of individuals with MR, not all are scientificially rigorous or pertinent to this manuscript. Therefore, while approximately 1,100 articles were considered, only 548 were admitted into this review.

Individuals from academic institutions and those involved in programs for individuals with MR through SOI, including Drs. Paul Berman, Sandra Block, Steve Corbin, Matthew Janicki, Steven P. Perlman, and H. Barry Waldman, also provided additional information. National U.S. datasets, including the National Health Interview Survey (NHIS), the National Health Expenditure Survey and the Survey of Income and Program Participation, also were reviewed to determine the availability of data related to individuals with MR.

Following a review of the definition and prevalence of MR, this report examines the physical, ocular, mental and dental health needs of individuals with MR. Next, the health care services available and accessible to this population are discussed. The report concludes with a list of recommendations, proposed to improve the health of individuals with MR.

DEFINITION OF MENTAL RETARDATION

Introduction

Valid measurement is the cornerstone of reliable epidemiological studies. Inappropriate measurement can result in a misclassification of either exposures or outcomes (in the case of this review, the classification of individuals with or without MR), which may lead to inconsistent or biased results (Armstrong et al., 1992; Kelsey et al., 1996; Rothman and Greenland, 1998). To ensure the correct classification of individuals into the categories of interest, definitions should be precisely specified from the outset of any study (Rothman, 1986). This is particularly important when examining social, psychological or cognitive impairments, such as MR, because often no objective biological measurement of these conditions exists (Kelsey et al., 1996).

An accurate and consistent definition of mental retardation is critical because of its impact on the prevalence, or count, of those with MR. However, despite the importance of consistency, MR is not always defined in the same way across research studies or service agencies, even within the same state (Koller et al., 1984; Borthwick-Duffy et al., 1994). While some definitions rely on IQ scores alone to classify individuals with MR, some only use adaptive behaviors for classification, and others include both IQ scores and measures of adaptive skills (Whitman et al., 1990; Borthwick-Duffy et al., 1994). In addition, many studies are based on broad cat-

egories of either severity (using labels such as mild, moderate, severe and profound MR) or etiology (utilizing the terms cultural/familial and organic MR).

Definition of Mental Retardation

The most commonly cited definition of MR comes from the AAMR. Most recently (1992), the AAMR has defined MR as the onset of significant limitations in both general intellectual and adaptive functioning during the developmental period (18 years and under). Intellectual limitations refer to an Intelligence Quotient (IQ) which falls two standard deviations below the population mean of 100 (<70), and adaptive functioning limitations refer to impairments in at least two out of ten skill areas (AAMR, 2000). MR is also defined in the Diagnostic and Statistical Manual of Mental Disorders, 4th edition (DSM-IV) by the American Psychiatric Association (APA). Similar to the AAMR definition, the DSM-IV has three diagnostic criteria for MR, including sub-average intellectual functioning (IQ <70), impairments in adaptive functioning and onset before age 18 (APA, 1994).

Although the core criteria for MR are similar between the AAMR and the DSM-IV definitions, there are important differences between the two. First, while the DSM-IV definition of MR has a strict IQ cutoff of 70, the 1992 AAMR definition indicates that if an individual presents with other signs of MR, the IQ cutoff may be raised to 75 (Schalock et al., 1994; Reiss, 1994). Second, although both definitions include a sub-classification system, the bases of the two sub-classification systems differ. The AAMR definition includes a scale measuring the extent of support needed to function in the environment, focusing on an individual's strengths, support systems, capabilities and interaction with the environment (Schalock et al., 1994; King et al., 1997). In contrast, the DSM-IV definition specifies the degrees of MR severity based on the level of IQ (mild=50–55 to 70, moderate=34–40 to 50–55, severe=20–25 to 35–40 and profound <20–25) (APA, 1994). Further, although not formally part of the definition of MR, the APA includes MR in the DSM-IV, thereby classifying MR as a mental disorder. The AAMR, however, explicitly states that MR is neither a medical nor a mental disorder (AAMR, 2000).

Considerable controversy exists over the use of the 1992 AAMR definition, however. While the definition was intended to broaden the definition of MR so that more individuals would be eligible for services (Reiss, 1994; MacMillan et al., 1995), several researchers believe that the 1992 definition compromises the conceptual and psychometric integrity of the 1983 definition of MR (MacMillan et al., 1995). Prior to 1992, for example, the AAMR definition focused on deficits at each developmental stage, using a severity scale (similar to that used by the APA) to emphasize IQ scores and expected age-appropriate behaviors (AAMD, 1983). In 1992, however, the AAMR increased the possible upper IQ score to 75, set general adaptive behaviors as a criterion and developed a sub-classification system based on levels of needed supports (MacMillan et al., 1993). Critics of the new definition believe that setting the IQ score limit to 75 may result in a classification of MR for individuals who have skills similar to their peers without MR, and may lead to an over-classification of minorities as having MR. Further, reliance on IQ has been criticized because of the cultural biases inherent in this measure (Hobbs, 1975; Zigler et al., 1984). Additional concern revolves around the measurement of adaptive behaviors and needed supports, which are thought to be poorly defined and to ignore developmental factors, thereby increasing the potential for misclassification. Consequently, some authors believe that a sub-classification system of MR should rely on etiology rather than poorly measured levels of supports (MacMillan et al., 1993).

The definitions of MR discussed thus far, however, ignore etiology. In contrast, Zigler and colleagues (1967; 1984; 1986; 1987a; 1991) argue that an appropriate classification of MR employs both IQ score and etiology of the retardation. Consequently, they suggest categorizing MR into cultural/familial and organic groups, based on the presence or absence of a known organic etiology. This two-group approach is one of the most well documented distinctions in the mental retardation literature over the last century.

Cultural/familial MR refers to individuals with IQs of 50–70, who do not have any identifiable physiological or genetic deficit. Although individuals with cultural/familial MR have lower intelligence than individuals without MR, the stages of cognitive development do not vary between these two groups. Those with cultural/familial MR, however, cognitively develop at a slower rate and do not reach the same cognitive levels as the general population. Consequently, individuals with the same mental age (or cognitive ability), regardless of chronological age, should perform similarly on cognitive-linguistic tasks. Emotional and motivational factors, however, influence the performance of individuals, and may account for certain behavioral differences between those of the same mental age (Zigler, 1967; Zigler et al., 1984; Zigler and Hodapp, 1986; Zigler and Hodapp, 1991).

In contrast, organic MR is attributable to an identifiable physiological deficit. Individuals in this group typically have IQ scores below 50, although individuals with IQ scores between 50 and 70 also can be classified as having organic MR. The cognitive development of individuals in this group is generally not thought to be comparable to those either without MR or with cultural/familial MR. The behavior of individuals in this group, then, is primarily the result of their physiological deficit (Zigler, 1967; Zigler et al., 1984; Zigler and Hodapp, 1986; Zigler and Hodapp, 1991). Some researchers, in fact, believe that all individuals with MR should be classified in the organic group. As science advances, they argue, physiological deficits will be discovered even among those with no present known organic etiology (Knobloch and Pasamanick, 1961 in Zigler and Hodapp, 1986; Richardson, 1981 in Zigler and Hodapp, 1986).

Even the two-group approach, however, may be too broad a classification system to adequately account for the heterogeneity of each group. While the cultural/familial group is thought to have at least 3 different subtypes (Zigler and Hodapp, 1986), there are hundreds of identified etiologies of organic MR (Lubs and Maes, 1977; Grossman, 1983). It is inaccurate, then, to view individuals with MR as fitting into one of two homogenous classes (Burack, 1990), particularly because many experts in the area embrace the theory of polygenic inheritance (for a description of the theory, see Zigler and Hodapp, 1986).

Although these different definitions of MR do overlap, and are therefore somewhat comparable, multiple classification systems can make comparisons across studies difficult. In addition, the consistency of MR classification has been further complicated by the use of imprecise labeling. In the U.S., for example, many individuals with mild MR have adopted the label "learning disabled," in order to avoid the stigma associated with "mental retardation" (Palfrey, 1994). The label "learning disabled," however, technically refers to individuals of normal intelligence who are not performing at their maximum ability level (AAMD, 1983). Moreover, in England, the term "learning disabled" is used to identify individuals with mental handicaps (Bhrolchain, 1989). This term, then, has become non-specific and includes individuals with a variety of conditions, including those both with and without MR. This type of imprecise labeling can be problematic, because it can lead to difficulties in conducting needs assessments and allocating services, as well as interpreting studies that use this classification.

Non-Categorical Classification of Mental Retardation

In addition to being defined inconsistently, MR is often grouped together with other conditions. For example, mental retardation is one of many conditions included in non-categorical classifications, such as "disability," which encompass conditions and diseases of different etiologies. In general, this approach has been adopted because it focuses on the similar medical, behavioral and cognitive problems found across illnesses, classifying individuals together based on functioning, rather than diagnosis. In contrast, the categorical approach uses diagnostic labels that do not convey the variability of morbidity within specific diseases (Stein et al., 1993; Stein and Silver, 1999). Eligibility for Social Security Income (SSI), for instance, was previously based on categorical diagnoses. As a result, SSI was denied to those who did not meet severity criteria with a single diagnosis, ignoring the cumulative functional effects of many conditions (Stein et al., 1993). Thus, the non-categorical approach is particularly beneficial for individuals with comorbid conditions, because it increases their likelihood to be eligible for a range of services. Consequently, the non-categorical approach is widely used in legislative initiatives, such as recent education- and employment-related amendments (Stein et al., 1993), and in policy initiatives put forth by agencies such as the National Policy Center for Children with Special Health Care Needs (Ireys et al., 1999).

Nevertheless, there are problems associated with the non-categorical approach. When different conditions are grouped together, it is difficult to determine the specific medical and social needs of an individual with a certain diagnosis. Disability, for example, is defined broadly to include several conditions, including MR, developmental disabilities, serious emotional disturbances, ongoing orthopedic disorders, genetic disabilities and chronic illnesses (Ireys et al., 1999). Since the needs associated with these different conditions vary greatly, using this term to represent any one of these groups gives very little information about the needs of an individual with a specific condition.

Summary and Implications

Because the definitions of MR used across research efforts vary, this report indicates the definition employed when describing study results. Although some research efforts focus on conditions such as Cerebral Palsy and Autism, these studies

are not included in this review, since individuals with these conditions do not uniformly have MR. Data on individuals with Down Syndrome (the one condition for which MR is a criterion) however, are presented. Further, although individuals with MR are included within non-categorical classifications, such as developmental disabilities, utilizing these terms in research makes it difficult to conclude anything specific about MR. Thus, in this report, efforts were made to avoid studies employing non-categorical definitions.

PREVALENCE OF MENTAL RETARDATION

Introduction

As mentioned above, prevalence data are crucial to the allocation of funding and the development of services, as well as to the comparison of findings between different research efforts. The prevalence of mental retardation is affected by many factors, including the definition of MR, the population studied and advances in medical technology. As discussed in the previous section, the definition of MR is an integral part of the determination of MR prevalence in the population. In addition, the population studied influences the prevalence found and indicates how generalizable that count may be. Most research uses either population-based or service use-based (administrative) data. While many European countries maintain registries of individuals with MR (making population-based studies common in those countries), no such registry or comprehensive national survey exists in the U.S. One national survey of the U.S. population, the NHIS, did have one question regarding MR, but because of the low prevalence found in 1981, the question was dropped in 1988 (Boyle et al., 1994). In addition, in 1994, a supplement to the NHIS (NHIS-D) was employed to collect population-based data regarding disabilities. The definition of MR used in the NHIS-D, however, was not consistent with either the AAMR or the APA definition; rather, the NHIS-D classification focused on previously diagnosed MR, conditions frequently associated with MR, and functional limitations in learning. Further, although MR involves disabilities of development, individuals with MR did not necessarily meet the criteria (three or more functional limitations) to be classified with a developmental disability, as defined by Public Law 98–527, in the NHIS-D (Research and Training Center on Community Living and Institute on Community Integration, 2000).

Since 1990, the Survey of Income and Program Participation (SIPP), another U.S. population-based survey, has documented MR among those households randomly selected for participation. It does not, however, make a specific effort to sample households of individuals with MR or other disorders. As a result, given the low probability of identifying individuals with MR in a randomly selected population, the SIPP cannot be considered a comprehensive account of those with MR (U.S. Bureau of the Census, 1999). In addition, both the NHIS and the SIPP underestimate the prevalence of disabilities among children and adults, because individuals living in institutions or group homes are excluded from the surveys (U.S. Bureau of the Census, 1999). In contrast to many European studies, then, most research efforts in the U.S. do not use population-based samples; rather, they rely on the number of individuals who utilize special services to estimate the prevalence of MR in the overall population.

Advances in medical technology have had a great impact on the prevalence of MR as well. Throughout the century, medicine's ability to treat the comorbid conditions of individuals with MR, and thus increase their survival time, has improved (Primrose 1984; Whitman et al., 1990). For example, individuals with Down Syndrome tend to suffer from thyroid and heart conditions, which can be better detected and treated today than in the past (U.S. Preventive Services Task Force, 1996; Saenz, 1999; Singer et al., 1995). Therefore, the increased life expectancy of these individuals results in a higher prevalence at any one point in time.

Further, several factors potentially affect the number of individuals who are actually born with MR. The rise in prenatal care, increased genetic screening and improvements in neonatal testing, for example, tend to increase the likelihood that children are born healthy. In contrast, other factors, such as increased prenatal substance use, tend to counter-act these effects and increase the prevalence of MR (Grossman et al., 2000). In sum, it is difficult to predict how the synergy of these factors affects the ultimate prevalence of MR.

U.S. Prevalence of Mental Retardation

It is estimated that as many as 2.0–7.5 million Americans of all ages may have MR, and that 1 in 10 families are directly affected by mental retardation (President's Commission on Mental Retardation, 1997; Grossman et al., 2000). Many reports have suggested that the population prevalence of MR in the U.S. is as high

as 3.0 percent (Tarjan et al., 1973; Zigler and Hodapp, 1986; President's Commission on Mental Retardation, 1997). A U.S. study using administrative data, however, found the prevalence among children to range from 0.3 percent to 3.1 percent in different regions of the country, with a national average of 1.1 percent (King et al., 1997). Similarly, the Metropolitan Atlanta Developmental Disabilities Surveillance Program, a population-based study which only used IQ score as the criterion for MR, found an overall prevalence of 0.9 percent among 3–10 year-old children (Boyle et al., 1996). Further, although the NHIS-D used its own definition of MR, it reported that .78 percent of the population had MR, with a prevalence of .45 percent for children 0–5 years, 2.0 percent for children 6–17 years, and .52 percent for individuals 18 years or older (Research and Training Center on Community Living and Institute on Community Integration, 2000).

Further, because teachers are often the first to notice mild developmental problems, most identified mild MR is initially detected during school years. The Atlanta population-based study, for example, indicated that while the prevalence of mild or moderate MR was only 0.5 percent for children 3–4 years of age, the prevalence rose to 1.2 percent, when older, school-aged children were studied (Boyle et al., 1996). It has been suggested, however, that only 50 percent of children with MR are identified at a young age because the failure to adapt normally and grow intellectually may not become apparent until later in life. Early identification may be further hampered by the fact that most pediatricians do not generally use standardized instruments to detect developmental delays (Grossman et al., 2000). In addition, because of their high level of functioning, those with mild MR are often unknown to special services once they leave school, and so, as adults, these individuals may not be counted as having MR in studies using administrative data. Moreover, many diagnosed children do not meet criteria when tested later in life. This suggests that either childhood or adult diagnoses are not adequately evaluating adaptive functioning (Forness, 1972 in King et al., 1997), or that IQ scores and functioning may vary over time (Zigler et al., 1984; Zigler and Hodapp, 1986; Loveland and Kelley, 1988 and Dykens et al., 1994 in King et al., 1997).

The majority of individuals with MR have historically been classified as having mild, cultural/familial MR. In the Atlanta population-based study 0.84 percent of 10 year-olds had IQs between 50 and 70 (mild MR), and 0.36 percent had IQs less than 50 (moderate to profound MR) (Yeargin-Allsopp et al., 1997). In addition, Boyle et al. (1996) reported that two-thirds of the children with MR in this study were classified as mild. Further, the prevalence and type of MR found in this study varied with race and gender, with Black males having percentages of mild, moderate and severe MR 3.1 times as high as those for White females. Percentages of profound MR (most likely organic), however, did not vary by race in this study (Boyle et al., 1996).

Part of the variation in the U.S. reported prevalence of MR is clearly due to differences between research efforts. For example, researchers making extrapolations based on birth estimates may report a higher prevalence than the number of cases counted in studies using either population-based or administrative data (Tarjan et al., 1973). The results of these latter studies, however, consistently indicate a prevalence of 1.0 percent.

International Prevalence of Mental Retardation

In other developed countries, the prevalence of mild MR appears to be lower than it is in the U.S. Percentages of MR or mental handicap in Sweden, for instance, have been estimated to be between 0.3 percent and 0.7 percent (Grunewald, 1979; Golding, 1982; Halldin, 1984, Zigler and Hodapp, 1986). Interestingly, although the prevalence of mild MR has been found to be lower in Sweden than in the U.S., the two countries have reported comparable percentages of severe MR (Zigler and Hodapp, 1986). Sweden's low prevalence of mild MR may seem surprising, given that at least some of the Swedish studies use a higher IQ cutoff (<80) to define this condition. However, Sweden has few psychologists, and testing is not as widespread there as it is in the U.S. (Zigler et al., 1984). Additionally, Swedish prevalence estimates of MR are based on the subjective opinions of teachers and clinicians, who are reluctant to label mildly cognitively impaired children (Zigler, 1987b). Further, since Sweden keeps a registry of individuals with MR, many Swedish studies are population-based, which may lead to a more accurate population prevalence than that estimated in the U.S. In addition, Sweden is a welfare state, and has many programs available for those with mild MR. As a result, many of these individuals are cared for in the community, and may never even be thought of as having MR until their IQs (at least males) are formally tested for entry into military service (Zigler et al., 1984; Zigler and Hodapp, 1986; Zigler, 1987b). When estimates from the community are combined with estimates from armed forces testing, the preva-

lence estimates for MR increase to 2.21 percent, similar to that found in other countries (Zigler, 1987b).

Other developed countries also have registries of mental retardation, which makes population-based studies more feasible than in the U.S. The overall prevalence of moderate and severe MR, arrested development or severe abnormality among children and adults in England has been found to range between 0.3 percent and 0.5 percent (Wing, 1971; Holt et al., 1973; Elliot et al., 1981; Goh et al., 1994). A study using a surveillance registry in British Columbia found the overall MR prevalence rate to be similar (0.4 percent), with 0.1 percent mild, 0.1 percent moderate, 0.05 percent severe, 0.04 percent profound and 0.01 percent unspecified MR (Herbst and Baird, 1983). In Ireland, using an IQ cutoff of 50 (severe MR), the rate of MR among adults 20–29 was found to range from 0.4 to 0.6 percent (Mallon et al., 1991).

In less developed countries, percentages of MR are generally found to be higher, from 1.6 percent–3.0 percent (Islam et al., 1993). However, several recent studies have found the prevalence of MR to be quite low. For example, in The People's Republic of China, the use of intelligence tests in several districts found a prevalence that ranged between 0.4 percent and 0.7 percent (Kuo-Tai, 1988). Similarly, a study in Cape Town, South Africa, using administrative data, found the prevalence of severe MR to be 0.3 percent (Finedlander et al., 1982), and a population-based study of prevalence in Bangladesh found a rate of 0.6 percent for severe MR and 1.4 percent for mild MR (Islam et al., 1993). Further, a study that went door-to-door in India, using the Binet-Simon scale to define MR as an IQ<80, has indicated a prevalence rate of 0.4 percent in the general population and 1.0 percent among children (Satapathy et al., 1985).

Summary and Implications

Most prevalence studies, then, utilize IQ alone to define MR. In the U.S., while the range of MR prevalence has been reported to be between 0.3 percent and 3.0 percent, most studies using administrative or population-based data have found a prevalence of 1.0 percent. In contrast, international studies, using population-based registries and somewhat different definitions of MR, report the prevalence to be less than 1.0 percent. The U.S. prevalence of severe MR, however, is comparable to that of other countries; in fact, some studies have found lower percentages of severe MR in the U.S. than in other countries. Since most mild or moderate MR is identified among school children in the U.S., the discrepancy in the prevalence of those conditions may due to international differences in school-based testing and services requirements (Palfrey, 1994), as well as mainstreaming practices. Further, the low prevalence of MR in some countries may be due to socio-cultural factors. In China, for example, there is a one child per family policy (Kane and Choi, 1999) and a strong preference for terminating pregnancies with genetic abnormalities (Mao and Wertz, 1997), both of which may affect the number of children born with MR.

These comparisons indicate that the international discrepancies in prevalence may, in part, be due to the different populations, definitions of MR, and methods of identification used in research studies. Moreover, cultural and political differences among countries may influence both the number of individuals with MR and the numbers that are counted in research studies. Despite these discrepancies, however, individuals with MR are present in all countries, and their needs, including their health needs, merit attention.

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CHAPTER 2.—PHYSICAL HEALTH CONDITIONS CONTRIBUTING TO THE MORBIDITY AND MORTALITY OF INDIVIDUALS WITH MENTAL RETARDATION

INTRODUCTION

For the purpose of this report, physical health conditions refer to chronic conditions that are common causes of death (such as cardiovascular diseases, cancer, diabetes, lung diseases, and unintentional injuries), risk conditions related to these chronic diseases, and childhood conditions and prevention measures that influence the long-term health and functioning of individuals (such as otitis media, pediatric asthma, child maltreatment and immunizations). Other physical health conditions, such as ocular and oral health conditions, are not included in this definition, and will be discussed in separate chapters.

Lacking large population-based studies, evidence documenting the prevalence of these physical health conditions among individuals with MR comes primarily from small community registries or administrative data from outpatient clinics or residential facilities. Since many individuals with MR do not receive services on a regular basis (Howells, 1986; Singer et al., 1986), however, studies using outpatient samples may underreport the prevalence of health conditions that do not always prompt medical interventions. Conversely, prevalence estimates from institutions may overreport the prevalence of certain health conditions, because those in hospitals or long-term residential settings are generally the most severely physically impaired and are likely to be monitored at regular intervals (Eyman et al., 1986).

Prevalence estimates are also affected by the identification of symptoms, either by the individuals with MR or by the caregiver. Often limited in communication skills, individuals with MR rely on caregivers to identify symptoms and report them to providers. Providers, then, must detect clinical manifestations of disease among individuals who lack communication skills to provide descriptions of symptoms. Consequently, syndromes based largely on reported symptoms rather than physical signs or specific routinely administered tests may also be underidentified.

MORTALITY AND MORBIDITY

Despite overall gains in life expectancy, gaps still exist between individuals with MR and individuals in the general population. In Western Europe and the United States, the overall life expectancy at birth is 74.0 to 76.5 years and life expectancy at 65 years is 81.7 to 82.7 years (Hoyert et al., 1997; WHO, 1997). In contrast, individuals with mild or moderate MR have an average life expectancy at 45 of 66.1 years, while those with severe MR have an average life expectancy at 45 of 53.6 years. Thus, the life expectancy of individuals with MR decreases with increased severity of MR and increased severity of physical impairments (Janicki et al., 1999; Eyman et al., 1990; O'Brien et al., 1991; Eyman et al., 1993), suggesting that those with mild or moderate MR have different health trajectories than those with severe or profound MR.

Further, life expectancy may be related to place of residence, although the results of the research are inconsistent. Hayden (1998) points out that some researchers have documented higher mortality rates among individuals with MR in institutions compared with those in the community, while others have suggested that individuals in the community have higher mortality rates (Strauss et al., 1998).

Living longer than individuals with severe MR, those with mild or moderate MR are more likely to have age-related health conditions similar to the general population. With a few exceptions, the prevalence of physical health problems (including cardiovascular disease, cancer, cerebrovascular disease, lung conditions and diabe-

tes) of individuals with MR is similar to that of the general population. This chapter will focus on the health conditions of adults and children with MR and specific health problems prevalent in individuals with Down Syndrome. The health problems selected for review were based on the leading causes of death in the U.S. population and the health priorities of *Healthy People 2000* and *Healthy People 2010* (U.S. DHHS 1990, U.S. DHHS 2000a).

Adult Health Conditions

According to the National Center for Health Statistics (NCHS), the most common causes of death in the United States include cardiovascular diseases, malignant neoplasms or cancer, cerebrovascular diseases, lung diseases, diabetes and unintentional injuries (Hoyert et al., 1999). Not surprisingly, the U.S. has made the prevention and treatment of these conditions a priority in *Healthy People 2000* and *Healthy People 2010* (U.S. DHHS 1990, U.S. DHHS 2000a). These same conditions also impair the health of individuals with MR. The most common causes of death among individuals with MR are cardiovascular diseases, respiratory illness and neoplastic conditions (Thase, 1982; Carter and Jancar, 1983; Dupont et al., 1987; O'Brien et al., 1991; Hayden 1998; Strauss et al., 1998; Janicki et al., 1999; Chaney and Eyman, 2000). This section will review the prevalence of these conditions among adults with MR.

Cardiovascular Disease

Cardiovascular disease is the leading cause of death in the U.S. and internationally, accounting for 31.4 percent of deaths in the U.S. general population and 30.9 percent of deaths in World Health Organization (WHO) member states (Hoyert et al., 1999; Turner and Moss, 1996; WHO, 1999). Manifestations of cardiovascular disease, including myocardial infarction, angina pectoris and sudden death, affect nearly 59.7 million individuals or 21.9 percent of the U.S. population each year (U.S. DHHS, 2000b). Consequently, *Healthy People 2000* and *Healthy People 2010* have heart disease as a priority area for health improvement in the U.S. (U.S. DHHS, 1990; U.S. DHHS 2000a).

As individuals with MR age, they suffer the same risk of cardiovascular disease as the general population. Cardiovascular disease is one of the most common causes of death among individuals with MR, accounting for 10.3 percent to 50.0 percent of deaths depending on the population studied (Carter and Jancar, 1983; Dupont et al., 1987; O'Brien et al., 1991). Prevalence estimates of cardiovascular disease in individuals with mild or moderate MR living in the community range from 6.7 percent to 55.2 percent, with individuals being at increased risk of disease as they age (Minihan, 1986; Minihan and Dean 1990; Janicki and Jacobson, 1986 and Badry et al., 1989 in Day and Jancar, 1994; Beange et al., 1995; Hand and Reid, 1996; van Schronjenstein Lantman-de Valk et al., 1997; Cooper 1998; Kapell et al., 1998). In addition, individuals with Down Syndrome are three to four times more likely to have cardiac conditions compared with individuals without Down Syndrome (Thase 1982; van Schronjenstein Lantman-de Valk et al., 1997; Kapell et al., 1998).

The prevalence estimates of cardiovascular disease, however, are lower among individuals with profound MR living in institutions (O'Brien et al., 1991; Turner and Moss, 1996). For example, O'Brien et al. (1991) found that 30 percent of all deaths among individuals with profound MR were related to heart disease compared with 44.4 percent among individuals with mild to moderate MR. If the lower prevalence is, in fact, real, it may be related to either lifestyle factors that influence blood pressure, cholesterol levels, obesity, cigarette smoking and physical activity (Pitetti and Campbell, 1991; Turner and Moss, 1996), or the fact that among the institutionalized, those who live longer are healthier. Alternatively, the difference may be due to incomplete measurement of the conditions under study. For example, Ziring et al. (1988) pointed out that 8.9 percent of those recently deinstitutionalized had previously undetected cardiac conditions, suggesting that cardiac conditions may be underdiagnosed among individuals in institutions.

Cancer

The second leading cause of death in the U.S. and the United Kingdom (U.K.) is cancer, accounting for 23.3 percent of deaths in the U.S. and 25.0 percent of deaths in the U.K. (Hoyert et al., 1999; Turner and Moss 1996). Cancer deaths are primarily attributable to lung cancer (49.5 per 100,000), breast cancer (25.6 per 100,000 women), prostate cancer (25.4 per 100,000 men) and colorectal cancer (17.6 per 100,000) (Ries et al., 2000). In the U.S., nearly 40 percent of individuals are diagnosed with cancer during their lifetime (U.S. DHHS, 1998). The most commonly diagnosed cancers are prostate (149.7 per 100,000 men), breast (109.7 per 100,000 women), lung (55.2 per 100,000) and colorectal (43.9 per 100,000) (Ries et al., 2000). Because cancer affects so many individuals in the U.S., the Surgeon General made

early detection, treatment and prevention of cancer a national priority in *Healthy People 2000* and *Healthy People 2010* (U.S. DHHS, 1990, U.S. DHHS, 2000a).

Cancer is also a health concern among individuals with MR. Cancer is among the most common causes of death among individuals with MR, with estimates ranging from 7.4 percent to 34.0 percent depending on the population studied (Carter and Jancar, 1983; Dupont et al., 1987). In fact, after adjusting for age, the prevalence of most cancers among individuals with MR living in the community is thought to be similar to that found in the general population. For example, in a study of the prevalence of cancer among older community residents with MR in the Netherlands, Evenhuis (1997) found cancer prevalence estimates similar to those in the Dutch population. He found that 22.9 percent of individuals with MR were diagnosed with cancer, including breast, prostate, lung, gastrointestinal and skin cancers.

One exception to these similar trends is among individuals with Down Syndrome (Jancar and Jancar, 1977; Turner and Moss 1996; Scholl et al., 1982; Baird and Sadovnick, 1988; Franceschi et al, 1991; Hasle et al., 2000). For example, in a recent study examining the prevalence of leukemia and solid tumors in the Danish Cancer Registry, Hasle et al. (2000) found that children with Down Syndrome are more likely to have leukemia compared with children of the same age in the general population (children ages 0–4 years, standardized incidence ratio: 56.4; children ages 5–19 years, standardized incidence ratio: 7.7). Individuals with Down Syndrome, however, were half as likely to have solid tumors compared with the general population, even after adjusting for age.

In contrast to community-based studies, in one institution in England, Cooke (1997) found that 13.6 percent of all deaths were due to cancer, an overall prevalence rate that was lower than the 26 percent found in the general population in England during the same time period. Although age- adjusted estimates were not presented, the prevalence of cancer among individuals with MR declined during a time when longevity increased in this population, suggesting that decreased life expectancy did not explain the lower prevalence of cancer among individuals with MR. Another important finding from this study was that the types of cancer varied between individuals with MR in the institution and those in the general population. In contrast to the leading cancer deaths in the general population, they found very few deaths due to lung, breast or prostate cancer; rather this study found a high proportion of gastrointestinal cancer among individuals with MR (55 percent in the MR population versus 26 percent in the general population). The high prevalence of gastrointestinal cancer was thought to be related to gastrointestinal reflux and chronic constipation that is common among individuals with MR living in institutions. Others have also documented a high prevalence of gastrointestinal cancer among individuals with MR in institutions (Jancar and Jancar, 1977).

The prevalence of cancer is also associated with severity of MR. In the U.S., O'Brien et al. (1991) found that among those individuals living in one southeastern residential facility, those with mild or moderate MR were more likely to die of cancer than individuals with profound MR. Additional studies examining the prevalence of cancer in the U.S. are limited. One study that examined mortality in 14 individuals with MR in the community provided anecdotal evidence that one of the 14 individuals died of undetected cervical cancer, a potentially avoidable cause of death (Kastner et al., 1993).

Cerebrovascular Disease

Cerebrovascular disease is a common term to describe ischemic and hemorrhagic strokes or transient ischemic attacks that result in a lack of blood flow to the brain. This disease is the third leading cause of death in the U.S. (Hoyert et al., 1999), with an estimated 731,000 incident (first time) strokes each year (Sacco et al., 1999). It is one of the most prevalent conditions among individuals 65 and older in the U.S. (NSA, 1999; U.S. DHHS, 2000a). In fact, more than 4 million or 4.3 percent of Americans 45 years and older are living with the effects of stroke (NSA, 1999). Like cardiovascular disease, the detection, prevention and treatment of cerebrovascular disease has been a national priority in *Healthy People 2000* and *Healthy People 2010* (U.S. DHHS, 1990; U.S. DHHS, 2000a).

Since the population of individuals with MR is aging, the risk of cerebrovascular disease, like that of cardiovascular disease and cancer, is increasing in this population (Turner and Moss, 1996). Few studies, however, have examined the prevalence of stroke among individuals with MR. In a community-based study in England, Cooper (1998) documented a cerebrovascular disease prevalence of 9.0 percent among individuals with MR 65 years and older, which she noted to be greater than that of the general population (although general population estimates were not provided). No individuals with MR under 65 years of age who participated in the study had a cerebrovascular disease. In another community-based study of 70+ year olds

in the Netherlands, Evenhuis (1997) found that 2.8 percent of individuals with MR reported a history of stroke, a prevalence estimate similar to that in the general population. Although it is unclear whether individuals with MR are more likely to have a stroke compared with the general population, it is clear that the aging MR population faces a serious risk of cerebrovascular disease.

Chronic Obstructive Pulmonary Disease (COPD) and Other Respiratory Conditions

Chronic obstructive pulmonary disease (COPD) is used to describe two respiratory conditions, chronic bronchitis and emphysema. Both conditions cause a shortness of breath and coughing that gets worse over time. COPD and other respiratory conditions, such as pneumonia and influenza, are the fourth and sixth leading causes of death in the U.S., respectively. COPD accounts for 4.7 percent of all deaths and pneumonia and influenza account for 3.7 percent of all deaths in the U.S. (Hoyert et al., 1999). According to the U.S. National Heart, Lung and Blood Institutes, over 13.5 million Americans report having COPD (5.1 percent of the U.S. population) (U.S. DHHS, 1995). Pneumonia and influenza have seasonal variations reaching their peak prevalence in winter. They are more commonly reported among the elderly and individuals with chronic health problems than among young, healthy individuals (CDC, 2000). In the year 2000, the U.S. Centers for Disease Control and Prevention reported a prevalence of 33 percent of individuals infected with influenza (CDC, 2000). Western European studies find a similar prevalence of COPD, pneumonia and influenza (Lung and Asthma Information Agency, 1995; WHO, 1999).

Most of the reviewed studies of individuals with MR report prevalence estimates of general respiratory conditions, inclusive of COPD and respiratory infections, although a few research efforts have focused on COPD or other specific respiratory conditions. Increased prevalence of respiratory conditions, and infections in particular, have been shown to be associated with increased age, institutional residence, severity of MR and severity of physical impairment. For example, studies conducted in the community and in institutions have shown that the probability of having a respiratory condition increases linearly with age (Janicki and Jacobson, 1986 in Day and Jancar, 1994); Day, 1987 in Day and Jancar, 1994).

Additionally, there is a higher prevalence of respiratory conditions among individuals 45 years and older living in institutions (1.1 percent to 33 percent) (Nelson and Crocker, 1978; Rubin, 1987; Day, 1987 in Day and Jancar, 1994; Minihan, 1986; van Schronjenstein Lantman-de Valk et al., 1997; Evenhuis, 1997), compared with those living in the community (1.5 percent to 5.1 percent) (Janicki and Jacobson, 1986 in Day and Jancar, 1994). Specifically, individuals with MR living in institutions are highly susceptible to respiratory infections. In fact, nearly one-half of all deaths in institutions are accounted for by pneumonia and influenza, with a disproportionate number of individuals having severe or profound MR (Polednak, 1975; O'Brien et al., 1991; Turner and Moss, 1996).

Differences between the prevalence of individuals living in the community and the prevalence of individuals with severe MR living in institutions are most likely related to the severity of both MR and physical impairments, as well as the associated limitations in physical activity. Among individuals living in residential facilities, for example, individuals with moderate or severe MR have been found to be more likely to have COPD compared with individuals with mild MR (van Schronjenstein Lantman-de Valk et al., 1997). Further, individuals living in institutions are more likely to be immobile and/or have difficulties swallowing and, thus, are more susceptible to respiratory infections (Turner and Moss, 1996; Kennedy et al., 1997). In addition, as a result of their congregate living arrangement, individuals with severe MR have greater exposure to infectious agents.

Individuals with severe MR are not the only subpopulation of individuals with MR to suffer from high rates of respiratory infections. Researchers have also suggested that young individuals with Down Syndrome are susceptible to such infections (Baird and Sadovnick, 1988), because of accelerated immunologic aging (Nespoli et al., 1993) and physical malformations that may hinder drainage of sinuses (Saenz, 1999).

Diabetes Mellitus

Diabetes mellitus is a disease in which the body has an inadequate supply of insulin, a hormone needed to metabolize food into energy. Obesity is a major risk factor of diabetes (CDC, 1998), and individuals with this disease are at higher risk of heart disease, stroke, high blood pressure, blindness, kidney disease, amputations and dental disease (CDC, 1998). Diabetes is the seventh leading cause of death in the U.S. (Hoyert et al., 1999), accounting for 2.7 percent of all deaths. Additionally, over 15.7 million individuals in the U.S. (5.9 percent of the population) and over 1.4 mil-

lion in the U.K. (3.0 percent of the population) have diabetes mellitus (CDC, 1998; Diabetes UK, 2000). With a high prevalence of the disease in the U.S., *Healthy People 2000*and *Healthy People 2010* have made preventing and reducing diabetes a priority in the nation's health (U.S. DHHS, 1990; U.S. DHHS, 2000a).

Although not a major cause of death among individuals with MR, diabetes and its associated risks are important health concerns. Individuals with MR have similar prevalence estimates of diabetes as individuals in the general population. In community studies in the U.S. and in Western Europe, the prevalence of diabetes among individuals with MR has been found to be 1.6 percent to 9.1 percent, with those over 65 having a two-fold increase in the risk of diabetes compared with those less than 65 years (van Schronjenstein Lantman-de Valk et al., 1997; Cooper, 1998; Kapell et al., 1998). Further, studies examining the prevalence of diabetes among those with MR residing in institutions found a lower prevalence than that found in community-based studies of individuals with MR (.8 percent–2.8 percent) (Hogg et al., 1988 in Day and Jancar, 1994; Minihan and Dean, 1990).

In addition, compared with the general population, individuals with Down Syndrome have an increased probability of being obese (Cronk et al., 1985 in Fujiura et al., 1997; Bell and Bhate, 1992). Perhaps as a result, there is some evidence to suggest that individuals with Down Syndrome have a higher probability of having diabetes and of having the disease at a younger age than individuals without Down Syndrome (Burch and Milunsky, 1969; Farquhar, 1969; Van Goor et al., 1997; Kapell et al., 1998).

Unintentional Injuries

Unintentional injuries (e.g., motor-vehicle, drowning, residential fires, poison consumption, falls) are the leading cause of death among young people (ages 1–34 years) and the fourth overall leading cause of death in the U.S., accounting for 4.1 percent of all deaths (Hoyert et al., 1999). The WHO also reports that 6.5 percent of deaths in WHO member states are attributed to unintentional injuries (WHO, 1999). Additionally, the NCHS reports that 31 million visits to the emergency room result from unintentional injuries each year (Burt and Fingerhut, 1998). The risk of injury is so great that most individuals will experience an unintentional injury at some point in their life. As a result of the high prevalence of injury, the Surgeon General has made reduction in mortality and morbidity due to unintentional injuries a national priority in *Healthy People 2000* and *Healthy People 2010* (U.S. DHHS, 1990, U.S. DHHS, 2000a).

Individuals with MR are at least as, if not more, likely to die from an unintentional injury compared with the general population. In a British Columbia study of the causes of death among individuals with Down Syndrome aged 30 and younger, Baird and Sadovnick (1988) reported that injuries occurred in the Down Syndrome population as frequently as in the general population (prevalence estimates ranging from <.1 percent to 8.2 percent). In a population-based study of deaths in Denmark, however, Dupont et al. (1987) found that individuals with mild or moderate MR aged 15–34 years were at increased risk of death due to accidents compared with the general population of the same age.

Although no studies could be found examining non-fatal accidents and injuries among adults with MR in the population, a few studies have examined sports-related injuries at Special Olympics, Inc. (SOI) events. Perlman (1994) summarizes the prevalence of sports-related injuries from SOI events in 12 states and the previous four world games, with a total of 701,988 participants. He reported an overall injury claim prevalence of .05 percent, with estimates ranging from .01 percent to .21 percent depending on the sporting event, although comparison to the general population is not possible since there are no comparable data for individuals without MR. McCormick et al. (1990) found a slightly higher prevalence of sports-related injuries at the Special Olympics competition in Galveston, Texas, with 3.5 percent of 777 athletes requiring medical care for sports-related injuries. Thus, like the general population, unintentional injuries and accidents are an important health concern among those with MR.

Health Behaviors

The prevalence of certain health behaviors, such as poor nutritional habits leading to obesity, decreased physical activity and smoking, has become a major concern to policy makers and researchers interested in the overall health of the nation. Obesity, physical activity and tobacco consumption are primary modifiable risk factors for most chronic diseases, and, as such, are listed among the leading health indicators for health in *Healthy People 2000* and *Healthy People 2010* (U.S. DHHS, 2000a).

Obesity

Obesity is associated with cardiovascular disease, breast, prostate and colon cancers, cerebrovascular disease and diabetes (National Task Force, 2000). According to *Healthy People 2010*, the number of overweight individuals has risen in the past four decades, with 11 percent of children ages 6 to 19 years being overweight or obese and 23 percent of adults being obese between 1988–1994 (U.S. DHHS, 2000a).

Obesity is more common among individuals with MR than in the general population, with overall prevalence estimates ranging from 29.5 percent to 50.5 percent (Simila and Niskanen, 1991; Bell and Bhate, 1992, Rimmer et al., 1993; Rubin et al., 1998). In fact, in a convenience sample of select participants, Touger-Decker and Matheson (2000) found that more than 66.0 percent of children with MR who participated in the New Jersey 2000 Special Olympic Games were overweight. The prevalence of obesity in the MR population has been found to vary with living situation and etiology of MR. Individuals living at home have the highest prevalence of obesity (55.3 percent) followed by those living in a group home (less than 16 residents) (40.9 percent), while individuals living in institutions (more than 100 residents) have the lowest prevalence of obesity (16.5 percent) (Rimmer et al., 1993; Prasher, 1995). In addition, individuals with Down Syndrome are 1.5 times more likely to be obese compared with individuals with other etiologies of MR (Bell and Bhate, 1992). With the majority of individuals with MR living in the community, it is imperative that obesity be considered a major health problem facing individuals with MR.

Physical Activity

Regular physical fitness is an important health maintenance activity that is associated with decreased body fat, decreased risk of cardiovascular disease and diabetes and enhanced psychological well-being (U.S. DHHS, 2000a). The U.S. Surgeon General has made regular physical activity a national health priority in *Healthy People 2000* and *Healthy People 2010*(U.S. DHHS, 1990, U.S. DHHS, 2000a). Among adults in the general population, only 15 percent participate in regular physical activity of 30 minutes per day and 40 percent engage in any leisure physical activity (U.S. DHHS, 2000a).

Like individuals in the general population, individuals with MR are unlikely to participate in physical activities, either because they lack the motivation or the opportunity to be involved in fitness programs (Rimmer, 2000). Few studies, however, exist on the prevalence of individuals with MR participating in routine physical activity. One study examined the leisure activities of 207 adults with MR living at home in Dublin, Ireland. In this study, McConkey et al. (1981) found that most individuals with MR ages 15–64 participated in activities that were sedentary, such as watching television (73.4 percent) and listening to the radio or records (41.1 percent). The prevalence of individuals with MR participating in outdoor sports ranged from 21.1 percent to 47.5 percent, with those more physically and mentally impaired being less likely to participate in outdoor sports. Although comparison to the general population is difficult given the lack of age-stratified information presented in the study, McConkey et al. (1981) reported the prevalence of physical exercise among non-retarded children 16–24 years as 44.0 percent. No information was presented on the prevalence of participation in outdoor sports. In a more recent U.K. health screening study of 120 individuals with MR living in the community, Martin et al. (1997) found that 48.2 percent had done some physical activity over the past four weeks compared with 93.5 percent in the general population.

More research has been done on cardiovascular fitness among individuals with MR (Beasley, 1982; Pitetti and Campbell 1991; Pitetti et al., 1993; Fernhall, 1993; Fernhall et al. 1998; Lancioni and O'Reilly, 1998). Cardiovascular fitness, an important aspect of physical activity, is related to the ability to perform light to moderate levels of physical labor. Fernall (1993), in a review of physical fitness among individuals with MR, reports that adults with MR have lower cardiovascular fitness levels than the general population, suggesting that individuals with MR may lead more sedentary lifestyles. Others have also found that individuals with MR have lower cardiovascular fitness levels compared with those in the general population (Pitetti and Campbell; 1991).

SOI has recognized the need for individuals with MR to have the opportunity to participate in physical activities, including team and individual sports. SOI provides year-round opportunities for individuals with MR to participate in sports training and athletic competition, with one of the explicit goals being development of physical fitness (SOI, 2000). Besides the primary athletic competition program, SOI also has developed basic fitness guides and training materials for SOI coaches to raise awareness of proper diet and nutrition among athletes. Further, these guides encourage athletes to participate in daily exercise not only during SOI programs but

also in their own home (Todd, personal communication). Additionally, SOI has developed four specific programs to encourage individuals at increased risk for sedentary lifestyles to participate in physical activities. These programs include a motor activities training program for individuals with severe MR, a unified sports program integrating individuals with mild MR with their peers without MR, a play activities program for young children with MR ages 6 and 7 years and an athlete leadership training program (Sharkey and Hunt, 1999).

Smoking

Cigarette smoking is a major preventable cause of disease and death in the U.S. and internationally (U.S. DHHS, 2000a; WHO, 2000). Smoking is a major risk factor for most of the major health conditions discussed above, including cardiovascular disease, cancer, cerebrovascular disease and lung disease. In 1997, 24 percent of adults in the U.S. reported smoking cigarettes (U.S. DHHS, 2000a). As a result, the Surgeon General and the WHO has made reduction in tobacco consumption a national and international health priority (U.S. DHHS, 2000a; WHO, 2000).

Prevalence estimates of tobacco consumption by individuals with MR vary by living condition and severity of MR. In a community-based study in the southern area of Melbourne, Australia, Tracy and Hosken (1997) found that 36 percent of individuals with MR sampled indicated that they smoked cigarettes compared with 26 percent in the general population. In a clinic-based study conducted in New Jersey, Hymowitz et al. (1997) found that 30 percent of 64 adults with mild MR reported that they were current smokers, which is only slightly higher than the smoking prevalence estimate for the U.S. general population. Burtner et al. (1995) examined the consumption of tobacco in a Florida residential facility for individuals with MR. With a prevalence estimate similar to that of the general population in 1995, they found that 20.5 percent of individuals with mild or moderate MR used tobacco products, including cigarettes, chewing tobacco, cigar and snuff. In comparison, only 4.3 percent of individuals with severe or profound MR used tobacco products. In a study of cardiovascular risk factors, Rimmer et al. (1994) examined the prevalence of smoking 10 cigarettes a day among individuals with MR living in a residential facility, living in a group home and living at home with family. They found that individuals with MR in the group home had the highest prevalence of smoking (20.8 percent of men and 6.7 percent of women) compared to individuals with MR living at home (6.9 percent of men and 2.1 percent of women) and individuals with MR living in an institution (3.8 percent of men, 0.0 percent of women). These studies suggest that individuals living in institutions and individuals with more severe MR are less likely to smoke, while individuals living in group homes and individuals with less severe MR have smoking habits similar to the general population.

The prevalence of smoking also has been studied in select SOI populations, with prevalence estimates below those observed in community-based and institution-based studies. Among 704 Special Olympic athletes who participated in the 1996 New Jersey Special Olympic Special Smiles program, 7.0 percent reported that they currently smoked (Feldman et al., 1997). A similar smoking prevalence of 4.3 percent was found among Special Olympic athletes who participated in the 1997 San Francisco Bay Area Special Olympics Special Smiles program (White et al., 1998). There is some evidence, however, that smoking status may not be accurately measured by self- report among individuals with MR. In a recent study at the 2000 New Jersey Special Olympic Games, 70 SOI atheletes aged 18 to 78 were asked to identify their smoking status and to complete a carbon monoxide (CO) test of smoking status. Among those who identified themselves as smokers, 27 percent had negative CO test results. Among those who identified themselves as non-smokers, 18 percent had positive CO test results (Giniger, 2000). Thus, although some studies have shown a lower prevalence of smoking among select populations of individuals with MR, the self-reported data from these studies may not adequately reflect the true prevalence of the population.

Many of the studies reported here suggest that individuals with mild or moderate MR and individuals living in group homes are as likely to consume tobacco products as individuals in the general population. Therefore, smoking education and prevention efforts are as essential for this population as it is in the general population.

Child Health Conditions and Prevention Measures

Otits media, asthma, child maltreatment and immunizations, were put forth as research priorities in the children's health arena by the Agency for Health Care Policy and Research, now called the Agency for Healthcare Research and Quality (U.S. DHHS, 1997a). Although these conditions and prevention measures are areas of concern among children in the general population, and, thus, among children with MR,

little information is available on the prevalence and long-term consequences of these illnesses and behaviors among children with MR.

Otitis Media

Young children are particularly susceptible to otitis media, or middle ear infections, because they have developing immune systems that have difficulty fighting infections, immature eustachian tubes that prevent optimal fluid drainage, and may have enlarged adenoids that interfere with the eustachian tube opening. Otitis media not only can cause severe pain, but, if left untreated, also can cause permanent hearing loss (U.S. DHHS, 1997b). Additionally, recurrent otitis media can have a negative impact on speech and language development, cognitive achievement and social and emotional development (Evenuis and Nagtzaam, 1997). Otitis media is one of the most prevalent childhood conditions, affecting 75 percent of children under the age of 3 years at least once (U.S. DHHS, 1997b). An estimated 17 percent to 29 percent of infants have one episode of acute otitis media and an estimated 26 percent of preschool children in the United States have recurrent otitis media (Lanphear et al., 1997).

The prevalence of otitis media among children with MR has not been adequately explored. There are some reasons to believe that children with Down Syndrome are at increased risk of middle ear infections due to midfacial malformations and increased susceptibility to infections (Saenz, 1999). Although not focused specifically on otitis media, one study of 293 residents of an English institution found that 40 percent of individuals with Down Syndrome and 29 percent of individuals with MR without Down Syndrome had ear, nose and throat conditions (Donague and Abbas, 1972). Dahle and McCollister (1986) compared the prevalence of ear problems in children with Down Syndrome to children with other forms of MR. They found that hearing impairment and infections were more prevalent among children with Down Syndrome. Given the potential impact of otitis media on development (Whiteman et al., 1986), early identification of middle ear infections among children with MR, who are already at risk for delays, is important.

Pediatric Asthma

Asthma is characterized by recurrent breathing problems brought on by inflammation of the lining of the lungs. The severity of asthma, as with most conditions, varies by individual. While some individuals are severely limited in their activities by the condition, others have only periodic symptoms of the disease. The negative consequences of asthma, however, can be avoided with appropriate disease management. Since 1980, the prevalence of asthma has been on the rise in all age, race and sex groups. In 1980, 4.2 percent of children were affected by asthma, but by 1994 the prevalence of asthma rose to 7.4 percent of children, a 74 percent increase over a 24-year period (U.S. DHHS, 2000c).

Little research has been done on the prevalence of asthma among children with MR. In a study of health status and needs of children with MR, Ackland and Wade (1995) reported the prevalence of medical conditions of 249 students in Victoria, Australia. With a prevalence estimate similar to that in the U.S. population of children, asthma was diagnosed among 6.4 percent of the children with MR.

No research exists on the negative consequences of asthma (such as reluctance to participate in physical activities) or on asthma management among children with MR, although one British study examined deaths from asthma in individuals less than 45 years old with MR. Reviewing death certificates of all residents in Southmead Health Authority, Stuart et al. (1990) found a high prevalence of asthma mortality among 5–44 year olds, with a morality rate twice that of the general U.K. population. Making confidential inquiries into the factors associated with the deaths, they found that several factors contributed to the high mortality rate, including communication difficulties between the patient and caregiver or provider, and delays in providers responding to an asthma attack. Given that disease management may be more difficult with children with MR who have limited communication skills compared with their peers without MR, increased attention should be given to self and caregiver management of this common childhood disease.

Child Maltreatment

Maltreatment is an all too common childhood condition in the U.S., with approximately 984,000 children being victims of substantiated or indicated abuse or neglect in 1997 (U.S. DHHS, 1999). The most common form of maltreatment is neglect (54 percent of victims), followed by physical abuse (24 percent), sexual abuse (13 percent), emotional maltreatment (6 percent) and medical neglect (2 percent). It is estimated that 1,196 of nearly one million victims of child maltreatment died from abuse or neglect in 1997 (U.S. DHHS, 1999). These estimates are based on reports by child protective services, which only account for those select cases that are

known to agencies, and, therefore, may under-represent the true prevalence of child maltreatment.

Children with MR also face serious consequences from abuse and neglect, although there is limited research on overall prevalence estimates of maltreatment in this population. As Waldman et al. (1999) point out, children who are abused are over four times as likely to have MR compared with non-abused children (Sullivan and Knutson, 1994 in Mansell et al., 1998). The causal direction in the association of child maltreatment and MR, however, is not clear. Physical abuse and neglect may result in MR (due to brain damage) or individuals with MR may be more likely to be abused and neglected.

In a study of 445 intellectually handicapped children in Castilla-Leon, Spain, Verdugo et al. (1995) interviewed professionals about signs of abuse and/or neglect. They found that 11.5 percent of children with an intellectual handicap aged 0–19 years had some evidence of maltreatment compared with 1.5 percent of children with no intellectual handicap. Among those who had evidence of maltreatment, 92 percent experienced physical neglect, 82 percent experienced emotional neglect, 65 percent experienced emotional abuse and 31 percent experienced physical abuse and 2 percent experience sexual abuse.

In addition, sexual abuse appears to be more prevalent among children with MR compared with children in the general population. Although not strictly focused on children with MR, Crosse et al. (1993) reported that children with disabilities are 1.8 times more likely to experience sexual abuse compared with children without disabilities (in Mansell et al., 1998). Other researchers have also found an increased prevalence of sexual abuse among children with disabilities (Sobsey and Varnhagen, 1989; Sobsey and Doe 1991; Sobsey 1994 and Valenti-Hein and Schwartz, 1995 in Reynolds, 1997).

Several researchers have speculated about the reasons for the increased prevalence of abuse among individuals with MR, and have cited stress and strain on the family, unrealized parental expectations of the child, emotional and social isolation of caregivers, children's inability to report abusive experiences, children's dependency on caregivers and lack of awareness about abusive situations as potential contributors (Solomons, 1979; Reynolds 1997; Waldman et al., 1999). Although there may exist a detection bias in who is identified as a victim, it is clear that individuals with MR are at least as, if not more, likely to experience maltreatment compared with their peers without MR.

Immunizations

Vaccines which prevent infectious diseases and death are considered one of the most important public health achievements of the 20th century (U.S. DHHS, 2000a). As such, vaccinations of children has remained a national health initiative in both *Healthy People 2000* and *Healthy People 2010* (U.S. DHHS, 1990; U.S. DHHS, 2000a). In 1998, 73 percent of children in the U.S. received routine vaccinations, including immunizations against Hepatitis B, diphtheria, tetanus, pertussis, polio, measles, mumps, rubella and Haemophilus influenzae type b (U.S. DHHS, 2000a; American Academy of Pediatrics, 2000).

Information on the immunization status for children with MR is sparse. In an early study of the medical care received by previously institutionalized children, Schor et al. (1981) found that 77.0 percent had up to date immunizations compared with 91.0 percent of children in the general population. Another study has examined the prevalence of routine immunizations among children with MR living in the community. McLaughlin et al. (1977) examined the immunization records of 134 children in a large northwestern school district, a sample population that may be generalizable only to the enrolled school population of children with MR and not to the institutionalized MR population. They found no statistical difference in the prevalence of completed immunizations between the 67 children with MR and the 67 age-, sex- and socioeconomic status-matched peers without MR (91 percent versus 81 percent, respectively).

Several studies have been conducted examining the prevalence and effectiveness of the Hepatitis B vaccine among children and adults with MR (Vajro et al, 1992; Arulrajan et al., 1992; Vellinga et al., 1999). These studies suggest that individuals with MR, specifically those with Down Syndrome and those residing in institutions, are at increased risk of Hepatitis B infection (Vellinga et al., 1999). Vajro et al. (1992) examined the seroconversion rate (the antibody response to a vaccine, which indicates that the vaccine was effective and that an individual is immune to the disease) of preschool children with Down Syndrome compared with children with other forms of MR. Despite prior evidence suggesting that individuals with Down Syndrome are more likely to lack an anti-Hepatitis B response compared with general population controls, they found that children in both groups had a complete

seroconversion. Given that children with MR, in particular those with Down Syndrome and those in institutions, are at increased risk of infection, administration of routine vaccines in this population is imperative.

Health Conditions Among Those with Down's Syndrome and Rationale for Increased Prevalence

Certain health conditions are particularly prevalent among individuals with Down Syndrome and warrant further discussion. For example, conditions such as orthopedic anomalies, congenital heart defects and thyroid disease, although relatively infrequent in the general population, can be life-threatening conditions for individuals with Down Syndrome.

Atlantoaxial Instability

Individuals with Down Syndrome have many orthopedic anomalies, but few are as life threatening as atlantoaxial instability. Atlantoaxial instability is a laxity in the movement between the first and second cervical vertebrae and, thus, increases the risk of spinal cord injury (Msall, 1999). It occurs in 10 percent to 40 percent of individuals with Down Syndrome, depending on the child's age and definition of instability (Tishler and Martel, 1965 and Alvarez and Rubin, 1986 in Cremers et al., 1993; Cope and Olson, 1987; Rubin, 1987; Pueschel and Scola, 1987; Pueschel, 1998). Despite the relatively high prevalence of atlantoaxial instability, there is no information about the prevalence of screening among individuals with MR, which may be due in part to the controversy surrounding the safety of the radiograph screening process and the questionable diagnostic value of the procedure (Pueschel, 1998). Therefore, effective and safe health screening procedures for asymptomatic atlantoaxial instability is an important consideration, in need of further exploration. Some researchers and providers, in fact, believe that atlantoaxial instability may limit an individual's ability to participate safely in sports (Saenz, 1999; Msall, 1999), while others have found restriction of activity based on the possibility of increased instability to be unnecessary for most children with Down Syndrome (Cremers et al., 1993; Morton et al. 1995).

Congenital Heart Defects

Children with Down Syndrome are significantly more likely to have a congenital heart defect than individuals in the general population. Approximately 40 percent to 60 percent of children with Down Syndrome have a heart defect (Spicer, 1984; Pueschel, 1990; Martin, 1997) compared with 0.8 percent in the general population (Mitchell et al., 1971; March of Dimes, 1999). Due to advancements in medical technology, however, survival for children with heart defects has dramatically improved (March of Dimes, 1999). Consequently, some physicians recommend that infants with Down Syndrome have electrocardiogram and echocardiogram screenings so that those in need can be referred to a specialist for medical management (Pueschel, 1990; Saenz, 1999). No studies were found that determine the screening rate of congenital cardiac conditions among individuals with Down Syndrome, however.

Thyroid Disease

Diseases of the thyroid, the organ that regulates the body's metabolism, can lead to blood pressure disturbances, fatigue, changes in appetite, weight disturbances, difficulty with concentration and changes in gastrointestinal regulation (Thyroid Society, 2000). Thyroid disease affects nearly 20 million or 1.4 percent of Americans (Thyroid Society, 2000). Compared with the general population, individuals with Down Syndrome have an increased probability of having a thyroid disorder, including hypothyroidism or hyperthyroidism, with prevalence estimates ranging from 3 percent to 50 percent depending on the population studied and criteria for diagnosis (Rubin, 1987; Pueschel, 1990; Dinani and Carpenter, 1990; Ali et al., 1999). Unlike individuals in the general population, who are at increased risk of thyroid disease with increased age, individuals with Down Syndrome are more likely to have thyroid disease at an earlier age. Those with Down Syndrome are thought to be at increased risk of thyroid disease because they often have autoimmune abnormalities (Kennedy et al., 1992; Ali et al., 1999) and accelerated immunologic aging (Nespoli et al., 1993).

Only one study could be found that examined the screening rate of thyroid disease among children with Down Syndrome. In an interview with Australian parents who attended a conference on Down syndrome, Selikowitz (1992) found that 64.7 percent of 132 school-aged children with Down Syndrome had been tested for hypothyroidism within the past 18 months. Even within this highly motivated and, presumably, informed population, then, the screening rate of thyroid disease was relatively poor. Because thyroid disease is so common among children with Down

Syndrome, regular screening and early detection of thyroid conditions is essential (Murdoch et al., 1977 in Martin, 1997; Noble et al., 2000).

SUMMARY AND IMPLICATIONS

Similar to individuals in the general population, individuals with MR are at risk for chronic medical conditions, including cardiovascular disease, cancer, cerebrovascular disease, lung conditions and diabetes. Individuals with MR are also susceptible to the primary risk factors of chronic diseases including obesity, decreased physical activity and smoking. As in the general population, the risk of disease among those with MR increases with age. In addition, the disease prevalence varies by severity of MR. Individuals with mild or moderate MR are more likely to have cardiovascular disease and diabetes compared with individuals with severe or profound MR, while those with severe or profound MR living in institutions are more likely to have respiratory conditions compared with individuals with mild or moderate MR.

Further, one group of individuals with MR, those with Down Syndrome, who have autoimmune abnormalities, are at increased risk of cardiovascular disease, leukemia, respiratory disease and diabetes. Not surprisingly, the risk factors associated with these diseases are more prevalent among those with Down Syndrome, namely obesity and decreased physical activity. Besides the common adult health conditions, individuals with Down Syndrome are also more likely to have diseases that are less common among individuals in the general population, including atlantoaxial instability, congenital cardiac conditions and thyroid disease.

Although common childhood conditions, such as otitis media, asthma and child abuse, have also been reported among children with MR, very little information exists about the prevalence or manifestations of these conditions in children with MR. The research that does exist suggests that children with MR are at increased risk of otitis media and of being maltreated.

Despite these increased risks of health conditions, however, little research exists on effective prevention programs and treatment strategies for this group of children and adults. One example of this lack of attention is the paucity of information on the immunization status of children with MR, one important public health measure. In addition, as will be discussed in a subsequent chapter, although individuals with MR have similar physical health problems as those in the general population, they are less likely to receive adequate medical services compared with those in the general population.

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CHAPTER 3.—MENTAL HEALTH DISORDERS AMONG INDIVIDUALS WITH MENTAL RETARDATION

INTRODUCTION

Individuals with MR, like their peers without MR, also suffer from considerable morbidity due to mental health problems. Since MR is a diagnosable mental health condition, the presence of both MR and another mental health disorder is known as dual diagnosis. Similar to the prevalence of MR and physical health conditions among those with MR, the prevalence of dual diagnosis varies with the populations studied (AACAP, 1999).

Although some large scale, population-based research exists, most studies of dual diagnosis are conducted with small sample sizes and use administrative data (e.g. hospital admission data) (Ineichen, 1984; Borthwick-Duffy and Eyman, 1990; Szymanski, 1994). The use of administrative data, however, may under- or over-estimate the prevalence of dual diagnosis in the population, depending on the sampling strategy used. For example, since many individuals with mild MR do not use services in the mental health care system (Borthwick-Duffy and Eyman, 1990), the reported dual diagnosis prevalence based on administrative data may under-represent the true prevalence of MR and mental health problems (Borthwick-Duffy and Eyman, 1990, King et al., 1997). Conversely, since those with psychiatric impairments are more likely to use services than those without impairments, these administrative estimates may over- estimate the prevalence of dual diagnosis. Research studying individuals referred to psychiatric services, for instance, may over-represent the population prevalence of individuals with mental health disorders (Borthwick-Duffy, 1994).

In addition to methodological constraints regarding sampling strategies, research on mental health disorders among individuals with MR also suffers from incon-

sistent diagnostic methods and difficulties diagnosing these conditions in this population. Nevertheless, the research presented in this chapter indicates a high prevalence of dual diagnosis.

DIAGNOSIS OF MENTAL HEALTH DISORDERS AMONG INDIVIDUALS WITH MR

In addition to sampling strategies, the methods used to diagnose mental health disorders influences the prevalence of such conditions among individuals with MR (i.e., dual diagnosis). While some research uses diagnoses noted in medical records (chart reviews), others use structured diagnostic assessments to identify dual diagnosis. When chart reviews are used, however, the prevalence of dual diagnosis has been found to be much lower than the prevalence as determined by the use of specific diagnostic tools (Reiss, 1990).

Further, while some researchers study mental health conditions as defined in the APA's *Diagnostic and Statistical Manual of Mental Disorders*, others use different scales and interview instruments for diagnosis (Crews et al., 1994). In addition, some professionals prefer the term "psychiatric illness," while others use the term "behavioral disorder" to indicate general mental health conditions (Szymanski 1994; Emerson et al, 1999; Moss, 1999). In this report, the term "mental health disorder" will be used to encompass both psychiatric conditions and behavioral problems.

In addition to the methodological issues involved in documenting dual diagnosis, there are two main challenges to the process of actual diagnosis of mental health disorders among individuals with MR. First, providers are often reluctant to diagnose mental health conditions among those with MR and second, there are often difficulties involved in identifying symptoms in this population. Historically, mental health conditions rarely were diagnosed in individuals with MR because many behavioral and emotional problems were thought to be either characteristic of MR (Eaton and Menolascino,1982; Zigler and Burack, 1989) or due to institutionalization (Day, 1993; Moss et al., 1997).

Although today it is recognized that mental health conditions exist in individuals with MR, and are separate from MR (Eaton and Menolascino, 1982; Borthwick-Duffy and Eyman, 1990), the presence of MR often diminishes the diagnostic significance of behavior that would otherwise be considered indicative of a mental health disorder. In other words, symptoms of a mental health disorder are often attributed to the MR, rather than evaluated as a potentially separate condition. Reiss et al. (1992), who termed this phenomenon *overshadowing,* provide an example of this in research conducted among psychiatrists evaluating hypothetical cases. Clinicians in this study were more likely to give the diagnosis of mental health disorder to an individual without MR than to a patient with the same case description plus the diagnosis of MR.

Symptoms of mental health conditions among individuals with MR, however, may be difficult to identify. Although, in principle, the diagnosis of mental health problems in individuals with MR is similar to that of individuals without MR (Tuiner and Verhoeven, 1993), diagnosis in this population can actually be quite difficult (Gabriel, 1994; Borthwick-Duffy and Eyman, 1990; Sturmey, 1999; Moss, 1999; Weissblatt, 1994; Moss et al., 1997; Prosser et al., 1998; AACAP, 1999), particularly among individuals with severe MR (Reiss and Valenti-Hein, 1994). Because of cognitive limitations, different developmental trajectories and limitations in lifestyle, individuals with MR will often present with different symptoms of mental health disorders, compared with those without MR (Reiss, 1982; Menolascino et al., 1986).

The most difficult conditions to diagnose among individuals with severe MR are psychosis and cognitive disorders (Weissblatt, 1994). For example, it is often hard to distinguish the effects of prolonged institutional care from symptoms of schizophrenia among those with severe MR (Ineichen, 1984). Further, severe cognitive limitations (known as*baseline exaggeration*), are common among those with severe MR, and make the identification of additional cognitive disorders challenging, if not impossible (Sovner, 1986 in Crews et al., 1994; Sturmey, 1999). Those with severe MR also may present with bland symptomatology, a phenomenon know as *psychosocial masking*, that makes diagnosis difficult as well (Sovner, 1986 in Crews et al., 1994; Sturmey, 1999).

In addition, those with severe MR may have limited communication skills, (referred to as *intellectual distortion*[Sovner, 1986 in Crews et al., 1994; Sturmey, 1999]) or maladaptive behaviors (referred to as*cognitive disintegration*[Sovner, 1986 in Crews et al., 1994; Sturmey, 1999]) due to their disability, and are often passive and compliant. Any of these conditions or behaviors may obscure or confound symptoms, making diagnosis difficult (Reiss et al., 1982; Gabriel, 1994; Borthwick-Duffy and Eyman, 1990; Crews et al., 1994; Prosser et al., 1998). For example, those with severe MR are frequently non-verbal, making conditions such as obsessive compul-

sive disorder difficult to diagnose (AACAP, 1999). As a result, diagnoses may depend on caregivers' abilities to identify symptoms and clinicians' observations (Brothwick-Duffy and Eyman, 1990; AACAP, 1999), rather than patients' accounts.

Since older children, adolescents and adults with mild MR are less likely to have trouble communicating, the process of diagnosis is much less difficult among these groups than among younger children or those with severe MR (Reiss and Valenti-Hein, 1994). As a result, individuals with mild MR may be more likely to be given a mental health diagnosis than those with more severe MR, although it is unclear whether those with more severe MR are less likely to have such problems or merely less likely to be identified with a problem (Borthwick-Duffy and Eyman, 1990; Crews et al., 1994).

Given these difficulties and the limited training that most clinicians have in working with individuals with MR, many providers prefer not to work with these patients. Consequently, when clinicians do treat individuals with MR, they are generally not experienced enough to make accurate diagnoses (Moss, 1999). An Australian study of psychiatrists, for instance, found that 75 percent of those surveyed felt that they hadn't received sufficient training in dual diagnosis, and 39 percent preferred not to treat the dually diagnosed (Lennox and Chaplin, 1996).

RATIONALE FOR MENTAL HEALTH MORBIDITY

Despite these diagnostic difficulties and ambiguities, higher rates of mental health impairments have been found among individuals with MR than in the general population (Zigler and Burack, 1989; Dosen, 1993; Moss, 1994; Moss et al., 1997; Embregts, 2000; Reiss, 1990). As Zigler and Burack (1989) point out, individuals with MR are capable of experiencing the same disappointments and difficulties as those without MR. Due to their increased sensitivity, however, an episode of "failure" may affect an individual with MR more than it would someone in the general population (Zigler and Burack, 1989).

Further, low intelligence may actually increase the risk of mental health problems for those who are aware of their limitations, as such a recognition may lead to self-concept problems and depressive reactions (Reiss et al., 1982; Crews et al., 1994). Similarly, parental and peer rejection, negative social relationships, limited supports and exposure to degrading situations may all make functioning in the community difficult (Siperstein et al., 1997, Eaton et al., 1982; Reiss and Benson, 1984; Taylor et al., 1987; Borthwick-Duffy and Eyman, 1990), and increase the likelihood of having mental health problems (Gabriel, 1994). Since individuals with mild or moderate MR are more likely to be living with their families and to be aware of their limitations, these individuals may be at higher risk than those with severe MR. Children with moderate MR, in fact, have been shown to be more likely to be rejected by parents than individuals with profound MR (Eaton et al., 1982; Eaton and Menolascino, 1982), and children with mild MR have been found to be more rejected by peers and express more dissatisfaction and anxiety about peer relations than those without MR (Taylor et al., 1987). As a result, both adults and children with mild or moderate MR may be at a higher risk of reacting to stressful life events with an affective disorder than those with severe or profound MR.

In addition, mental health conditions may be more common among individuals with MR due to biological risk factors (Reiss et al., 1993). Those with MR, for example, may suffer from more genetic abnormalities and brain damage than the general population (Moss et al., 1997), which may be associated with a higher prevalence of mental health conditions. For example, central nervous system damage, which is common among those with MR, may increase the vulnerability of individuals to develop other mental health disorders (Eaton and Menolascino, 1982).

PREVALENCE OF MENTAL HEALTH MORBIDITY

General Mental Health Morbidity

Mental health disorders in individuals with MR have been estimated to occur at a rate 3–6 times greater than that in the general population (Eaton and Menolascino, 1982; Walters et al., 1995; Maino, 1996). Research studies among individuals without MR have reported a prevalence of mental health disorders ranging from 7 percent–26 percent (Bergeron et al., 1992; Surgeon General, 1999). The prevalence of dual diagnosis reported in both the U.S. and international literatures, however, is extremely inconsistent. In fact, a review of the literature done by Borthwick-Duffy (1994) indicates that studies using different definitions and sampling strategies estimate the prevalence of dual diagnosis to range from less than 10 percent to more than 80 percent. Lower prevalence estimates, however, are obtained when client records are examined, while higher prevalence estimates are documented from clinical evaluations. Reiss (1990), for instance, found the prevalence

of mental disorders in a community-based day program to vary from 12 percent, using chart reviews alone, to 39 percent using screening surveys and 60 percent using clinical evaluations.

Among adults, the Surgeon General (1999) reports that 21 percent of those in the general population suffer from a mental health condition. Similarly, research using administrative data in the U.S. has found percentages of dual diagnosis to range from 17 percent to 36 percent (Reiss, 1990; Jacobson, 1982; Iverson and Fox, 1989 in Borthwick-Duffy, 1994). Further, European studies estimate the prevalence of dual diagnosis to range from 12 percent of individuals with severe MR, using administrative data (Kushlick, 1975 in Borthwick-Duffy, 1994), to 27 percent, using population- based data (Lund, 1985 in Borthwick-Duffy, 1994). Given that much of the literature indicates a higher prevalence of specific mental health disorders among individuals with MR, this reported similarity in prevalence estimates between adults with and without MR may be due to the methodologies used or the specific conditions studied in these research efforts.

Among children, 5 percent–21 percent of the general population have been reported to have mental health conditions (Bergeron et al., 1992; Szymanski, 1994; Costello 1999; Friedman et al., 1998; Surgeon General, 1999). Conversely, studies using administrative data in the U.S. have found the prevalence of dual diagnosis to range from 14 percent to 60 percent (Jacobson, 1982; Menaloscino, 1965 and Chess and Hassibi, 1970 in Borthwick-Duffy, 1994). As described above, research using populations referred to psychiatric services report a higher prevalence of dual diagnosis (87 percent) (Phillips and Williams, 1975 in Borthwick-Duffy, 1994).

Further, studies using administrative data in Europe have found a prevalence of dual diagnosis among children similar to that reported in the U.S., ranging from 9 percent to 43 percent (Kushlick, 1975, Haracopos and Kelstrup, 1978 and McQueen et al., 1987 in Borthwick-Duffy, 1994). In addition, while Rutter et al.'s (1970) British population-based study reported a prevalence of mental health disorders of about 7 percent among children without MR (Borthwick- Duffy, 1994), European population-based studies report a prevalence of childhood dual diagnosis of 30 percent to 64 percent (Rutter, 1970 in Borthwick-Duffy, 1994; Gillberg et al., 1986).

Mental Health Morbidity and Severity of MR

As with other health conditions described in this report, the prevalence of diagnosed mental health disorders tends to vary with severity of MR. Many studies have found that the prevalence of mental health disorders is highest among individuals with mild MR (Iverson and Fox, 1989 in Borthwick-Duffy, 1994; Borthwick-Duffy and Eyman, 1990; Jacobson, 1982). For example, administrative data from California indicates that 16 percent of individuals with mild MR are psychiatrically diagnosed, while only 5.7 percent of those with severe or profound MR have a dual diagnosis (Borthwick-Duffy and Eyman, 1990). These findings are consistent with the notions that MR is easier to diagnose among those with mild or moderate MR, and that because of their living situations and awareness, those with mild or moderate MR are more prone to mental health disorders than individuals with severe or profound MR.

International studies, however, indicate a different association. Many population studies in Europe have found that individuals with more severe MR have a higher prevalence of dual diagnosis (Rutter, 1970 in Borthwick-Duffy; Gillberg et al, 1986; Gostason, 1985 in Borthwick- Duffy, 1994; Goh and Holland, 1994). For example, one European study reported prevalence estimates of such disorders to be 60 percent among those with an IQ<60, and just over 20 percent among those with an IQ between 60 and 69 (Birch et al., 1970).

The discrepancy between American and European research has several potential explanations. First, the inconsistent finding may suggest that there is no association between severity of MR and dual diagnosis (McCaren and Bryson, 1987 in Borthwick-Duffy, 1994). Second, the inconsistencies may be due to research methodology. Studies based on administrative data found more dual diagnosis among individuals with mild MR, while studies using population-based data reported a higher prevalence among those with severe MR. This may be because those with severe MR and a mental health condition may be more likely to be institutionalized, and thus less likely to be captured in administrative data.

Third, studies that examined specific conditions indicate that the association may vary with condition (Corbett et al., 1975 and Koller, 1983 in Borthwick-Duffy, 1994; Reid, 1980). For example, based on a survey of individuals referred to an outpatient clinic for those with developmental disabilities, Reiss (1982) reports that 20 percent of individuals with mild MR were diagnosed with depression, compared with none of those with severe MR. As discussed above, individuals with mild MR may have

difficulties "fitting in" with their peers and feel unaccepted and thus unsatisfied with their lives, which may lead to depression. Those with severe MR, however, may not be as aware of their social situation, and thus may not be as depressed.

This same study, however, found schizophrenic symptomatology to be more frequently diagnosed among those with severe MR (46.7 percent) than among individuals with mild MR (16.7 percent). Although a psychotic diagnosis is more difficult among individuals with severe MR than those with mild MR, individuals with severe MR are more likely to live in institutions, where experienced mental health providers are more accessible than they are in community settings. In fact, those living in institutional care have been reported to have a higher prevalence of dual diagnosis (18.6 percent) than individuals living with their families (5.1 percent) (Borthwick-Duffy and Eyman, 1990). The higher prevalence among those with severe MR in Europe, then, may be due to the distribution of individuals among residential settings, with individuals in institutions receiving more comprehensive diagnostic assessments than those living in the community.

SPECIFIC CONDITIONS

Adult Mental Health Conditions

The types of mental health disorders found in those with MR are similar to those found in their peers without MR (Reiss et al., 1982; Eaton and Menolascino, 1982). Among adults in the general population, the most common mental health disorders consist of anxiety disorders, affective disorders and substance abuse. Although schizophrenia is not very prevalent, it merits attention due to its severity and persistence (Surgeon General, 1999). The most common disorders cited among adults with MR and intellectual disabilities in both the U.S. and Australia are anxiety disorders, psychotic disorders and personality disorders (Reiss, 1990; Lennox and Chaplin, 1996; Moss et al., 1997). As discussed above, affective disorders are important, albeit less common, conditions among individuals with MR, and thus warrant attention here as well. Further, individuals with Down Syndrome report a high prevalence of dementia. In contrast, there has been a much lower prevalence of substance abuse reported among individuals with MR than in the general population (Reiss, 1990; Moss et al., 1997). The prevalence of the above mentioned conditions will be presented in this chapter.

Anxiety Disorders

Although earlier research studied the condition "neurotic disorder," this term, which closely resembles the presently used term "anxiety disorder," is no longer used in the mental health literature. For the purposes of this report, "anxiety disorder" will be used to refer to both anxiety and neurotic disorders.

Anxiety disorders usually present as clinically significant unpleasant emotions, such as fear, dread and alarm, in the presence of stressors. The Surgeon General (1999) reports that between 13.1 percent and 18.7 percent of the general population suffers from an anxiety disorder. In contrast, Reiss (1990) found that 31.4 percent of individuals at a community-based day program for individuals with MR suffered from an anxiety problem, and that for 6.4 percent, anxiety was a major problem.

Although the prevalence of anxiety among individuals with MR is higher than that in the general population, anxiety disorders have been found to be difficult to diagnose in individuals with severe MR. In fact, although Day (1983) reports a prevalence of anxiety disorders of 28 percent among individuals with MR, only 4 percent of these cases were among moderately and 0 percent were among severely mentally handicapped individuals (Fraser and Nolan, 1994).

Obsessive-compulsive disorder (OCD), one of many anxiety disorders, is characterized by recurrent obsessions or compulsions that are severe enough to be time-consuming or cause marked distress or significant impairment (APA, 1994). This condition generally manifests itself in adolescents or young adulthood (Surgeon General, 1999); its prevalence in the general population is estimated to range from 1 percent–2.4 percent (Surgeon General, 1999).

Among individuals with MR, the prevalence of OCD has been reported to be 3.5 percent (Fraser and Nolan, 1994). OCD may present atypically among individuals with MR, with hand washing, self-injury, sterotypic movements and anxiety dominating the symptomatology (King, 1993 in Verhoeven and Tuiner 1999; Stavrakaki, 1999). In contrast, the most common symptoms in the general population include concern over order, symmetry or contamination with germs or bodily fluids, doubts, or loss of control of violent or sexual impulses (Surgeon General, 1999).

Anxiety is important to understand, as severe cases can be violent and disruptive, and interfere with functioning (Stavrakaki, 1999). Acting out may be particularly problematic among individuals with MR, as a result of the frustrations associated

with an inability to verbally communicate (Fraser and Nolan, 1994). While some believe that this condition is associated with the same pathology that causes the intellectual disability, others associate anxiety disorders with trauma and abuse (Stavrakaki, 1999).

Affective Disorders

Affective disorders include states of abnormally low mood (depressive disorders) and states of abnormally elevated mood (manic states) (Clarke, 1999). In the general population, the one-year prevalence of affective disorders is reported to be 7 percent (Surgeon General, 1999). In comparison, the point prevalence among institutionalized individuals with MR has been reported to be 8.9 percent (Crews et al, 1994). As discussed above, this percentage among institutionalized individuals with MR may reflect the low prevalence of depression diagnosed among those with severe MR. Crews et al. (1994), however, did find that over half of those with dual diagnosis (57 percent) suffer from an affective disorder. The most common mood disorders include major depression and bipolar disorder (Surgeon General, 1999).

Depression is an affective disorder characterized by low mood and decreased energy (Clarke, 1999). In the general population, the prevalence has been estimated to be between 5 percent and 25 percent (Stavrakaki, 1999; Kessler et al., 1996). Among adults with MR, depressed mood is the most common psychological symptom (Laman and Reiss, 1987; Fraser and Nolan, 1994). The administratively determined prevalence of diagnosed depression among individuals with MR, however, has been estimated only to be between 3 percent and 6 percent (Reiss, 1990). In fact, among individuals with mild MR receiving disability benefits from New York State, 6.2 percent were found to have depressed mood (Laman and Reiss, 1987). Although these percentages may seem low compared with the general population prevalence, they may underestimate the true prevalence of depression in the population with MR because they are derived from service-based data. Further, experts in the field believe depression to be underdiagnosed among those with MR (Reiss, 1994), due in large part to an atypical presentation, including aggressive behavior, self-injury, psychomotor agitation and irritable mood (Meins, 1995 in Verhoeven and Tuinier, 1999).

The causes of depression among individuals with MR are thought to be the same as among those in the general population, and include biological and genetic factors, as well as stressful life events, which may be numerous in this population (Stavrakaki, 1999). In addition, depression is often associated with the low levels of social support and poor social skills often experienced by individuals with MR (Schloss, 1982 in Benson et al., 1985; Reiss and Benson, 1983; Laman and Reiss, 1987). The impact of depression on individuals with MR is significant, as it has been shown to be associated with aggressive behavior, anger, irritability, antisocial behavior and conduct problems (Laman and Reiss, 1987).

Bipolar disorder consists of manic behavior or the combination of both mania and depression, and is not as common as depression. The Surgeon General Report (1999), in fact, reports about 1.7 percent of the general population (age 18 to 54) to have a bipolar disorder. Among individuals with MR, bipolar disorder is rarely reported. This may be due to the atypical symptomatology, namely perplexity, lability and irritability, associated with bipolar disorder in this population. In fact, whether this symptomatology should be characterized in this domain is a matter of debate (Verhoeven and Tuinier, 1999).

Psychotic Disorders

Psychotic disorders have been defined as disturbances of perceptions and thought processes (Surgeon General, 1999). While the Surgeon General (1999) estimates the prevalence of nonaffective psychosis in the general population to be 0.2 percent, Reiss (1990) found a prevalence of psychosis among individuals with MR attending a community day program to be 5.8 percent.

Schizophrenia, one type of psychotic disorder, is characterized by distortions in thinking and perception, and inappropriate or flat mood states (Clarke, 1999). In general, schizophrenia is believed to occur in only 1.0 percent of the general population, compared with 3.0 percent of the population with MR (Clarke, 1999; Weissblatt, 1994; Fraser and Nolan, 1994; Surgeon General, 1999). Using administrative data, however, Eaton and Menolascino (1982) found the prevalence of schizophrenia to be 21 percent, and Reiss (1982) reported it to be 30.3 percent, among adults with MR.

In the past, stereotypic behaviors seen in individuals with severe MR were thought to be indications of schizophrenia (Hayman, 1939). Due to the degree of language skills necessary to diagnose schizophrenia, however, this view is no longer accepted. In fact, as described above, schizophrenia is currently rarely diagnosed among individuals with severe MR, and some do not believe that it is even possible

to make such a diagnosis among individuals in this group (Reid, 1993). Rather, a less specific diagnosis of psychotic disorder, not otherwise specified, is often made among individuals with severe MR (AACAP, 1999).

Personality Disorders

Personality disorders consist of long-term problems in adjustment (Reiss et al., 1993). The Surgeon General (1999) reports an anti-social personality prevalence of 2.1 percent among the general population, and Kassen et al. (1999) report that 23.6 percent of their community sample of young adults were diagnosed with a personality disorder.

Although some debate exists as to whether personality disorders can be observed among individuals with low mental age (such as children or those with MR) (Reiss, 1994), these disorders have been cited as some of the most common psychiatric diagnoses among individuals with MR (Day, 1985 in Fraser and Nolan, 1994; Emerson et al., 1999). Reid and Ballinger (1987), for example, found that among individuals in a hospital for the mild/moderately handicapped, 56 percent had abnormal personalities and 22 percent suffered from personality disorders (Fraser and Nolan, 1994). Similarly, Duncan et al. (1936) found 33 percent of institutionalized individuals with MR to have a personality disorder, and Eaton and Menaloscino (1982) reported that 27.1 percent of individuals at a community-based program had one of these conditions.

Dementia

Individuals with MR are now surviving long enough to be at risk for age-associated conditions such as dementia of the Alzheimer type (Tuinier and Verhoeven, 1993). Adults with Down Syndrome, for example, experience a higher rate of dementia at a relatively earlier age than those without Down Syndrome (Janicki and Dalton, 2000). In fact, most individuals with Down Syndrome who live past 35 years show Alzheimer-like neuropathology (Holland, 1994).

Substance Abuse

Substance use has not been found to be as common among individuals with MR as in the general population (Koller et al., 1982 and MacEachron, 1979 in Edgerton, 1986). The general population prevalences for illicit drug use and alcohol use have been reported to be 11.9 percent and 66.4 percent, respectively (SAMSHA, 1998). In contrast, of the 205 participants at a community- based day program for individuals with MR, Reiss (1990) found that no individuals suffered from alcohol or drug abuse, and Glick and Zigler (1995) reported that 3.5 percent of 112 psychiatric inpatients with mild MR were substance abusers. In addition, Edgerton (1986) reported that among four samples of adults with MR living in a variety of community settings, individuals were less likely to use alcohol or other drugs than a comparison group of individuals without MR. This is somewhat surprising, since studies in both the U.S. and the U.K. have found large numbers of deinstitutionalized individuals with other mental health disorders, who may face the same adaptation problems as those with MR, to be substance users (Arce et al., 1983, Wynee, 1984 and Melick et al, 1979 in Edgerton, 1986).

Child Mental Health Conditions

Due to the changing nature of children's environments and brain development, the sociocultural environment in which they live affects their mental health even more than it does that of adults (Surgeon General, 1999). Among children in the general population, the most common mental health disorders are anxiety disorders, affective disorders, and attention deficit and disruptive disorders. These same disorders, with the addition of schizophrenia, are also the most commonly reported mental health disorders among children with MR (Chess and Hassibi, 1970 in Borthewick-Duffy, 1994 Embrets, 2000; Szymanski, 1994; AACAP, 1999).

Anxiety Disorders

The combined prevalence of anxiety disorders is higher than that of virtually all other mental disorders of childhood and adolescence (Costello et al., 1996 in Surgeon General, 1999). The Surgeon General (1999) reports the one-year prevalence of anxiety among 9–17 year olds to be 13 percent. In contrast, a small study of a psychiatric clinic for children with mental handicaps under the age of 16 reported 22 percent to suffer primarily from an anxiety disorder (Reid, 1980). Since children with MR are more dependent on their caregivers than children without MR, they may be more likely to react to changes in their routine, resulting in higher prevalence estimates of anxiety in this population.

Affective Disorders

Depression in childhood differs from depression among adults. Children with major depression, for example, do not experience psychotic features as often as depressed adults do, and when they do, the features are not presented in the same manner. Further, major depression is more likely to be associated with an anxiety disorder in children than in adults. In fact, two- thirds of children and adolescents with major depressive disorder also suffer from another disorder (Surgeon General, 1999).

In the general population, the prevalence of depression has been estimated to be 6.2 percent for children 9–17 (Surgeon General, 1999). As with adults, the prevalence of depression is lower among individuals with MR, and it is easier to diagnose among children with mild MR than those with more severe MR. In Sweden, the prevalence of depression has been reported to be 1.5 percent among children with severe MR and 4 percent among children with mild MR. Again, this may be due to the lack of family and peer support felt by children with mild MR, who are often expected to function "alone" in the general society to a greater extent than other subgroups of MR (Stavrakaki, 1999).

One reason that depression is important to consider among children is that it increases the risk of suicide. In fact, over 90 percent of children who commit suicide are believed to have had a mental disorder. Among children in the general population, the prevalence of suicide is 1.6 per 100,000 among 10–14 year olds and 9.5 per 100,000 among 15–19 year olds (Surgeon General, 1999). Although many people do not associate suicidality with MR, in a study of a psychiatric hospital, 21 percent of admissions for dual diagnosed youth demonstrated suicidal behavior either before or during the hospitalization (Walters et al., 1995).

Attention Deficit and Disruptive Disorders

The most common attention deficit and disruptive disorders include attention deficit/hyperactivity disorder (ADHD) and conduct disorder. In the general population, the prevalence of ADHD is estimated to be 3 percent to 5 percent (APA, 1999). Among children with MR, poor attention and hyperactivity, the hallmarks of ADHD, are common reasons for mental health referrals (AACAP, 1999). Since most of the criteria used to diagnose ADHD are based on behavioral observation, not verbal communication, this disorder can be diagnosed fairly easily among non-verbal individuals with MR (AACAP, 1999). Consequently, the prevalence of ADHD among those with MR, 4 percent–11 percent, has been found to be somewhat similar to that in the general population (Feinstein and Reiss, 1996 in AACAP, 1999; APA, 1999).

Further, among children with Down Syndrome, Green et al. (1989) found that even between the ages of 2 and 4 years, a discrete group could be identified as showing measurable attention deficit. Although this study was small, the authors concluded that the deficit was not associated with mental age, parenting style or medical factors; rather, they believed it to be intrinsic to Down Syndrome (Stores et al., 1998). ADHD is important to recognize because although many children outgrow their symptoms, children with ADHD often develop other disruptive disorders in their teenage years (Surgeon General, 1999).

Children or adolescents with conduct disorder behave aggressively by fighting, bullying, intimidating, physically assaulting, sexually coercing, and/or being cruel to people or animals (Surgeon General, 1999). Conduct disorder among children in the general population has been reported to range from 6 percent–16 percent among boys and 2 percent–9 percent among girls (APA, 1999).

Among individuals with MR, a Swedish population-based study found that 4.5 percent of those with severe MR and 12 percent of those with mild MR suffered from conduct disorder (Gillberg et al., 1986). Similarly, reports by Gath and Gumley (1986; 1987) indicate that 11 percent of school children were rated to have conduct disorder by parents and teachers. A much smaller study of a psychiatric clinic for children with MR, however, reported that as many as 45 percent of the study population primarily manifested a conduct disorder (Reid, 1980), and Richardson et al. (1985) reported that 33 percent of children and adolescents with mild MR suffer from this disorder (AACAP, 1999). Although the prevalence, then, is not clear, a significant percentage of children with MR do suffer from conduct disorder. Given that rates of depression, suicidal thoughts, suicide attempts, and suicide itself are all higher in children diagnosed with a conduct disorder (Shaffer et al., 1996 in Surgeon General, 1999) than in children in the general population, this is an important condition to consider.

Psychotic Disorders

Since schizophrenia tends to develop during adolescence and young adulthood, the appearance of schizophrenic symptoms before age 12 is rare (APA, 1999; Rapoport,

2000). Schizophrenia develops very slowly in children, so that most children with schizophrenia show delays in language and other functions long before their psychotic symptoms appear (Rapoport, 2000).

Perhaps because of its rarity, no reports of the prevalence of schizophrenia among children in the general population were identified for this report. The classification of children with schizophrenia among children with MR may be more frequent because some believe that children with psychosis often function at a mentally retarded level (Eaton and Menolascino, 1982). Eaton and Menolascino (1982), in fact, found the prevalence of schizophrenia to be 5 percent among children (<21 years) with MR, and 9 percent of children with Down Syndrome have been reported by parents and teachers to be classified as psychotic (Gath and Gumley, 1986; Gath and Gumley, 1987). A Swedish population-based study, however, found a lower prevalence of schizophrenia among children, with 1.5 percent among individuals with severe MR and 1 percent among those with mild MR (Gillberg et al., 1986).

Other Disorders

Since MR can be a feature of pervasive developmental disorder (PDD), children with both of these conditions usually are not considered to be dually diagnosed. Because of its prevalence among individuals with MR, however, PDD deserves mention here. PDD is indicated by disordered cognition or thinking, difficulty in understanding and using language and difficulty in understanding the feelings of others or the world around them (Surgeon General, 1999). Autism, the combination of social, communication and imagination-behavior restriction (Wing and Gould, 1979 in Gillberg, 1999), is the most common form of PDD. Autism has been reported in .05 percent–.17 percent of children in the general population, in 5 percent among those with mild MR, and in 15 percent among individuals with moderate or profound MR (Bryson et al., 1998 in Gillberg, 1999; APA, 1999).

In addition, many studies report the prevalence of behavioral disorders, although the definition of this term is not clear. Nevertheless, this "condition" certainly represents functional issues and thus merits attention in this report. In the U.K., the prevalence of severe behavioral disorder among children with severe MR has been reported to be 20 percent among children and adolescents (Wing, 1971 and Kushlik and Cox, 1973 in Holt, 1994).

Further, among children with Down Syndrome, about 30 percent have been rated by their parents and teachers as behaviorally disordered (Gath and Gumley, 1986; Gath and Gumley, 1987). Although a British study of children indicated that those with Down Syndrome had a higher prevalence of behavioral disturbance than those without Down Syndrome, however, children with other intellectual disabilities showed a higher prevalence than either of these groups (Stores et al., 1998).

SUMMARY AND IMPLICATIONS

Due to differences in methodology and diagnoses, comparisons of the prevalence of mental health disorders between individuals with MR and the general population are challenging at best. Further, given that dual diagnosis tends to be difficult, if not impossible, among individuals with severe MR, the percentages of mental health conditions reported here may underestimate the true percentages in this population. Nevertheless, the studies highlighted here indicate a high prevalence of dual diagnosis.

The mental health conditions reported among individuals with MR are very similar to those found in the general population. Adults with MR tend to suffer less from substance abuse than those in the general population, but are more often diagnosed with anxiety disorders, psychotic disorders and personality disorders. Although affective disorders are less often diagnosed in adults with MR than in the general population, the prevalence of these conditions is believed to be higher than the cited studies indicate. In addition, individuals with Down Syndrome suffer from dementia as they age, and children with MR tend to suffer from anxiety disorders, affective disorders, psychotic disorders, ADHD and conduct disorder.

Most U.S.-based studies find a higher prevalence of depression among individuals with mild or moderate MR than those with more severe MR. Schizophrenia, however, has been found to be more prevalent among individuals with severe MR. These associations may be due to the nature of the disorders. Since individuals with mild MR are more likely to live with their families, and experience and be aware of every-day stressors, they may be more susceptible to affective disorders than those with severe MR. In addition, the relationship between schizophrenia and severity of MR may be due to difficulties in diagnosing certain mental health conditions among individuals with MR. Because those with severe MR are more likely to live in institutions than those with mild MR, the former group may have greater access

to experienced mental health care providers, who are capable of making difficult diagnoses.

Further, European studies have found more mental health disorders among individuals with severe MR. This may be due to the types of populations and disorders studied, differences in diagnostic practices or the distribution of individuals among residential settings. For example, since in the U.S. dually diagnosed individuals with severe MR are more likely to live in institutions than with their families, they may not be captured in research using administrative data. Given that European studies tend to use population-based samples, they may be more likely to diagnose mental health disorders among individuals with severe MR than administrative studies conducted in the U.S.

While in the past most individuals with MR in the U.S. received mental health care in the institutions in which they lived, most Americans with MR currently live in community or family settings. As a result, accessible and appropriate community-based services are imperative in order to identify and treat mental health disorders in this population.

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CHAPTER 4.—OCULAR IMPAIRMENTS AMONG INDIVIDUALS WITH MENTAL RETARDATION

INTRODUCTION

As previously discussed, the prevalence of a condition will vary with changes in the population studied. Most research on ocular anomalies among individuals with MR analyzes administrative data, examining individuals who use services in the community. Depending on the population sampled, however, administrative studies may under- or over-estimate the true prevalence of ocular impairments among individuals with MR.

PREVALENCE

Available data suggest that ocular impairments (refractive errors, strabismus, cataracts, keratoconus, nystagmus and poor visual acuity) are more common among individuals with MR than those without MR (Polcar, 1983; Levy, 1984; Ronis, 1989; Maino, 1996). While 25 percent of children in the general U.S. population are reported to be ophthalmologically impaired, as many as 72 percent of children with MR have been so categorized (Lawson and Schoofs, 1971). A similar, if not more striking pattern can be seen among older adults. For example, while in the general population 0.6 percent of those between age 60 and 69, and 9.0 percent of those over 80 have been reported to have ocular impairments (Thielsch et al., 1990 in Evenhuis, 1995), research in the Netherlands has found a prevalence of 18 percent–20 percent of moderate, and 8 percent of severe, visual impairment among institutionalized individuals over 60 years of age. Other studies have reported percentages of ocular impairments in individuals with MR over 50 years to range from 8 percent to 50 percent (Janicki and Jacobson, 1986, Day, 1987, Moss, 1991 and Van Schrojenstein Lantmann-de Valk et al., 1992 in Evenhuis, 1995).

The most common cause of decreased vision in individuals with MR is uncorrected refractive errors (Maino, 1996), such as astigmatism, farsightedness and nearsightedness. While 15 percent–30 percent of the general population has a refractive error (Sullivan, 1988 and Regenbogen, 1985 in Gnadt and Wesson, 1992), 20 percent –60 percent of individuals with MR in the U.S. and Canada have been reported to require correction of refractive anomalies (Levy 1984; Woodruff et al., 1980; Gnadt and Wesson, 1992; Maino, 1996).

Similarly, British research of administrative data on individuals with MR found the prevalence of refractive errors to be 30 percent (Aitchison et al., 1990), and an administrative study in Japan reported the prevalence of such impairments to be

even higher. In this study, Kuroda et al. (1987) found that more than 80 percent of children with MR had refractive errors (Kuroda et al., 1987).

International research on specific sub-populations of those with MR, however, has found slightly lower prevalence estimates of refractive errors. A Swedish study of institutionalized individuals with MR, for example, reported that 23 percent had a considerable refractive error in the best eye (Jacobson, 1988), and in Hong Kong, the prevalence of refractive errors among those with profound MR (IQ<25) has been reported to be 24 percent (Kwock et al., 1996).

In addition, research has examined the prevalence of specific types of refractive errors, including astigmatism, hyperopia (farsightedness) and myopia (nearsightedness). Woodruff et al. (1980), for example, found the prevalence of astigmatism among institutionalized Canadian individuals with MR to exceed 30 percent. Further, Levy (1984) found higher percentages of hyperopia/astigmatism than myopia/astigmatism among Canadian adults with MR, although the difference was more pronounced among males than females, and a similar pattern can be seen among individuals without MR. In contrast to most Western studies indicating that hyperopia is more prevalent among individuals with MR than myopia, however, Kwok (1996) found myopic and hypermetropic astigmatisms to be equally prevalent in Hong Kong.

Further, strabismus (the inability of both eyes to fixate on a target simultaneously because of ocular muscle imbalance) has been attributed to uncorrected refractive errors (Woodruff, et al., 1977). Similar to other visual impairments, the prevalence of strabismus among individuals with MR exceeds that of the general population (Woodruff, 1977). While the prevalence of strabismus in the general population has been found to range from 3.7 percent to 9.5 percent (Levy, 1984; Block et al., 1997), the prevalence ranges from 21 percent to 41 percent among American and Canadian individuals with MR (Lawson and Schoofs, 1971; Woodruff et al., 1980). Similarly, Aitchison et al. (1990) found the prevalence of strabismus to be 31 percent in a British administrative sample.

The prevalence of cataracts (opacity of the lens of the eye, the capsule or both) and keratoconus (swelling and scaring of the cornea) among individuals with MR also has been reported to be much higher than that in the general population (Woodruff, 1977; Levy, 1984). For example, while the percentage of lens anomaly reported for adults without MR has been 1.42 percent, administrative data in the 1980's indicated that between 2.68 percent (females) and 5.36 percent (males) of Canadian adults with MR suffered from cataracts. In this same study, keratoconus also was reported to be more common among males than females with MR (Levy, 1984). British administrative data, however, indicates the prevalence of cataracts to be as high as 11 percent (Aitchison et al., 1990). These high prevalence estimates among individuals with MR may be due to the association between cataracts, keratoconus and Down Syndrome (see below).

Severity of MR has also been found to be associated with the prevalence of visual impairments, with individuals with severe MR having more ocular problems than those with mild or moderate MR. Woodruff (1980), for example, found higher percentages of astigmatism among institutionalized Canadian individuals with severe MR than among those with mild or moderate MR, but reported no difference in corneal power between these categories. Further, Hirsch (1959) reported that individuals with higher intelligence tend to be more myopic, and those with lower intelligence to be more hyperopic (Manley and Schuldt, 1970). In contrast, McCulloch et al. (1996) did not find a significant trend between severity of disability and refractive error among Scottish individuals with MR. They did, however, find a relationship between severity of MR and visual acuity (clearness or distinctness of vision). While 88 percent of institutionalized individuals with mild intellectual disability had good visual acuity, only 60 percent of those with severe disability and none of those with profound disability achieved this level. Similarly, the prevalence of strabismus in this study ranged from 25 percent among those with mild MR to 60 percent among those with profound MR.

OCULAR CONDITIONS AMONG SPECIFIC POPULATIONS

When the Special Olympics, Inc. (SOI) population was studied at the 1995 International Summer Games, the prevalence of overall ocular problems (29 percent) was comparable to that found in institutions (Block et al., 1997; Woodruff, 1980). Specifically, 27 percent suffered from poor visual acuity, 85 percent had refractive errors, 28 percent suffered from astigmatism, and 18.5 percent had strabismus (Block et al., 1997). Further, at the 1999 World Summer Games, the Special Olympics Opening Eyes Vision Health Program found as much as 25 percent of the screened population to have some form of strabismus (SOI, 1999).

Individuals with Down Syndrome are at a particular risk for ocular anomalies as they age (Aitchison et al., 1990). In fact, among older adults, ocular impairments tend to occur at an earlier age among individuals with Down Syndrome than in the general population (Flax et al., 2000). Visual impairments, then, are of growing concern due to the increased longevity of patients with Down Syndrome (Aitchison et al., 1990).

A Swedish study conducted in the late 1980's highlights the association between age and ocular impairment among individuals with Down Syndrome. Among 50 institutionalized patients with Down Syndrome, Jacobson (1988) found that 22 had a visual impairment, and 14 of the 22 (64 percent) had acquired the impairment as adults. Further, although Lyle and Jaeger (1972) reported the prevalence of keratoconus to range in the literature from 1 percent to 8 percent among children with Down Syndrome, Jacobson found a prevalence of 30 percent among institutionalized adults with Down Syndrome (Jacobson, 1988).

Generally, those with Down Syndrome are more likely to suffer from strabismus, nystagmus (constant, involuntary, cyclical movement), cataracts and keratoconus (Woodruff, 1977; Hestness et al., 1991; Millis, 1985 in Woodhouse et al., 1997), compared with individuals without Down Syndrome. The prevalence of strabismus has been reported to range from 22 percent to 43 percent among individuals with Down Syndrome (Berk et al., 1996 in Block et al., 1997; Shapiro and France, 1985; Pires Da Chuna et al., 1996). In addition, the prevalence of cataracts, which tends to increase as individuals with Down Syndrome age (Jacobson, 1988), has been found to range from 13 percent to 54 percent (Shapiro and France, 1985; Jaeger, 1980 in Pires Da Chuna et al., 1996), and the prevalence of keratoconus has been reported to be 15 percent (Shapiro and France, 1985), among individuals with Down Syndrome.

Further, despite the association between age and ocular anomalies in this population, children with Down Syndrome tend to have a high prevalence of ocular impairments. For example, one study found that among children with severe MR, 70 percent of those with Down Syndrome had poor visual acuity, compared with 30 percent of children without Down Syndrome (Gardiner, 1967). Additionally, a Brazilian study found a high prevalence of strabismus (38 percent) among children with Down Syndrome, although this condition was significantly more frequent among older children (Pires Da Chuna et al., 1996). Moreover, refractive errors have been reported in over 40 percent of children with Down Syndrome (Gardiner, 1967).

Not surprisingly, then, Welsh researchers have reported that children with Down Syndrome have a higher prevalence of astigmatism compared with children without Down Syndrome, although this difference was only statistically significant among older children (Woodhouse et al., 1997). The Brazilian study mentioned above also found a high percentage of astigmatism (60 percent), compared with strabismus (38 percent), among children with Down Syndrome (Pires Da Chuna et al., 1996). Further, a British study found more myopia than hypermetropia among children with Down Syndrome. Gardiner (1967) reports that among children with severe MR, 50 percent of the children with Down Syndrome were myopic and 15 percent were hypermetropic, while only 3 percent of children without Down Syndrome were myopic, and as many as 40 percent were hypermetropic.

RATIONALE FOR INCREASED PREVALENCE

Part of the increased prevalence of ocular impairments among individuals with MR may result from the proportion of aging people with intellectual disabilities, which has grown due to medical and social advances (Flax et al., 2000). In fact, as detailed above, older individuals with MR, particularly those with Downs's syndrome, report a higher prevalence of visual impairments than individuals of the same age in the general population.

In addition, the high prevalence of visual impairments among individuals with organic MR may be due to the condition that caused the MR, which may actually restrict ocular growth (Woodruff, 1980). According to Gardiner (1967), for example, most eye anomalies among individuals with Down Syndrome are due to a lack of coordination of the eye during its growth. Further, as mentioned above, Down Syndrome is often associated with cataracts, which can cause visual loss (Evehuis et al., 1997). In other cases, however, visual impairment may result from long-term medication use, which often has ocular side effects (Bartlett, 1987; Polcar, 1983; Maino, 1996). Since individuals living in institutions are often prescribed more drugs than those in the community, this may account for the higher prevalence of visual impairments among individuals with severe MR, who are more likely to be institutionalized than those with mild or moderate MR (Woodruff et al., 1980;

Polcar, 1983). Additionally, as will be discussed in chapter 6, a loss of visual efficiency and acuity may occur over time due to inadequate detection and treatment.

SUMMARY AND IMPLICATIONS

The prevalence of ocular deficits among individuals with MR, then, varies, depending on the population studied. Nevertheless, most research efforts have found high percentages of visual problems within this population. The most common conditions among individuals with MR, both in the U.S. and internationally, appear to be refractive errors and strabismus, although the distribution of hyperopia and mypoia tends to vary with the population studied. In addition, individuals with severe MR tend to have more visual anomalies than those with mild MR. While this observation may be due to the etiology of the MR, it may also be due to the increased medication use associated with the institutionalization of individuals with severe MR. Further, those with Down Syndrome are highly likely to have strabismus, cataracts and keratoconus, particularly as they age.

Identifying ocular impairments in childhood is important because early correction can prevent further impairments over time. Further, visual impairment can limit the range of experiences and information available to a child, and thus, have a significant impact on a child's emotional, neurological and physical development (Mervis et al., 2000). This may be particularly important for children with MR. Combined with their other impairments, untreated or mistreated visual deficits may be a more devastating obstacle to children with MR (who may rely greatly on good functional vision) than to other children (who may be better able to compensate for visual impairments in other ways) (Gardiner, 1965; Krekling and Anderson, 1974; Markovits, 1975; Ronis, 1989; Maino, 1996; Evenhuis and Nagtzaam, 1997). Correcting ocular anomalies, then, can lead to both better functioning in society and educational and social benefits for children, adults and their families. Given this, it is crucial that ocular problems are identified early and, when possible, corrected.

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CHAPTER 5.—DENTAL HEALTH AMONG INDIVIDUALS WITH MENTAL RETARDATION

INTRODUCTION

Poor oral health can have dramatic effects on an individual's quality of life. In fact, it can cause difficulties with eating, speech impediments, pain, sleep disturbances, missed days of work or school and decreased self-esteem (Locker et al., 1987; Hollister et al., 1993 and Broder et al., 1994 in Perlman and Broder, 1996). In recognition of the importance of oral health to individuals, the U.S. Surgeon General and the World Health Organization have made oral health a national and international priority (U.S. DHHS, 1990; U.S. DHHS, 2000a; U.S. DHHS 2000b; WHO, 2000).

The overall oral health of a population can be described by DMFTs, which characterize the lifetime prevalence of dental caries in an individual or population by summing the number of decayed teeth (D), the number of missing teeth (M) and the number of filled teeth (F) (WHO, 2000). DMFTs range from 0 to 28 or 32 (depending on the inclusion or exclusion of wisdom teeth), with 28 or 32 indicating that all teeth have problems related to dental caries. Among 12-year old U.S. children, the average DMFT is 1.4 (WHO, 2000), while the average DMFT among U.S. adults aged 35–44 years is 13.6. Among Western European countries, DMFTs for 12-year old children range from .9 to 6.1 with a mean DMFT of 2.6. Adults from Western European countries have DMFTs between 8.8 to 22.9 (WHO, 2000).

Besides dental caries and tooth loss, other oral health concerns include gingivitis (inflammation of the gums) and other periodontal diseases (loss of connective and bone tissue that support the teeth). According to the National Health and Nutrition Examination Survey III, 48 percent of the U.S. adult population had gingivitis and 22 percent had other periodontal disease between 1988–1994 (U.S. DHHS, 2000a).

Although the overall oral health of the population is improving, disparities still exist in oral health needs among subpopulations (Waldman, 1996; U.S. DHHS, 1999; U.S. DHHS, 2000a; U.S. DHHS 2000b). Individuals with MR, for example, have poorer overall oral health and oral hygiene compared with the general population (Haavio, 1995; Feldman et al., 1997; Waldman et al., 1998). The oral health and hygiene of individuals with MR is associated with severity of MR, etiology of MR, residential arrangements and age of the individual (Gabre and Gahnberg, 1997). The prevalence estimates among those with MR reported in the literature, however, are subject to the some of the same problems as the prevalence estimates of other health conditions. Namely, oral health prevalence estimates are based on administrative data or small community registries that may not adequately reflect the true prevalence in the population. Additionally, the methodologic rigor with which some of these published studies were conducted is somewhat questionable, in that they provide little information about the measurement of MR or its severity among individuals, inconsistent information about a comparison group and few, if any, statistical tests for comparison between groups of individuals.

PREVALENCE

Dental problems are among the top ten limiting secondary conditions among individuals with MR (Traci et al., in press; Szalda-Petree et al., in press). According to a recent pilot study of consumers of Montana Developmental Disability services (79.8 percent of whom had mental retardation), Traci et al. (in press) found that the estimated prevalence rate of oral hygiene problems was 451 per 1000 individuals with developmental disabilities. Like the general population, one of the most common oral health problems of children and adults with MR is dental caries. National and international studies, however, do not provide definitive data on the prevalence of dental caries among those with MR relative to the general population (Haavio, 1995; Shapira et al., 1998; Waldman et al., 2000a). The majority of authors have found that individuals with MR have similar prevalence estimates of dental caries to those of the general population (Pollack and Shapiro, 1971; Svatun and Heloe, 1975; Brown and Schodel, 1976; Tesini, 1981; Pieper et al., 1986; Costello 1990; Whyman et al., 1995; Gizani et al., 1997; Cumella et al., 2000). Some researchers,

however, have found lower prevalence estimates of dental caries among individuals with MR, and others report higher prevalence estimates of untreated carries in this population (Tesini, 1981; Girgis, 1985; Forsberg et al., 1985; Barnett et al., 1986; Kendall, 1991).

Nowak (1984), for example, examined the dental health of 3,622 disabled individuals aged 0–16+ years living in the community. Based on examinations by dental hygienists, they found an average DMFT score of 6.44 among individuals with Down Syndrome, and an average DMFT score of 6.73 among individuals with other etiologies of MR, compared with an average DMFT score of 6.68 among individuals in the general population. They found, however, that the proportion of missing teeth (M) to filled teeth (F) was much higher among individuals with MR compared with the general population, suggesting that extraction, rather than restoration, is the primary treatment of dental problems among those with MR (Svatun and Heloe, 1975; Nowak, 1984).

Alternatively, other researchers have found that those with MR have a lower prevalence of dental caries (0.4 caries per individual) compared with the general population (Girgis, 1985; Forsberg et al., 1985, Barnett et al., 1986). This low prevalence of dental caries is primarily found among individuals with severe MR living in institutions (Gabre and Gahnberg, 1994; Shapira et al., 1998). In fact, Butts (1967) found that children with severe MR living in institutions had fewer dental caries than children with mild or moderate MR. It is likely that the low prevalence of dental caries found among those with severe MR living in institutions relative to the general population results from the prior removal of decayed teeth and the low sugar diet served in institutions (Tesini, 1981). Some authors, however, have focused on the prevalence of untreated caries, rather than DMFT scores, which quantify the number of both treated and untreated caries. These studies report that both children and adults with MR have more untreated caries than the general population (Costello 1990; Cumella et al., 2000).

Another common oral health problem among children and adults with MR is gingivitis, with prevalence estimates of 1.2 to 1.9 times the estimates of the general population. Studies on the oral health of individuals with MR, conducted in communities in the U.S. and internationally, report prevalence estimates of gingivitis in the range of 60 percent to 97 percent among individuals with MR compared with an estimates of 28 percent to 75 percent in the general population (Murray and McLeod, 1973; Sturmey and Hinds, 1983; Vignehsa et al., 1991; Kendall, 1991; Cumello et al., 2000; Tesini, 1981; American Dental Association, 2000). Those who are older, those living in institutions and those with Down Syndrome tend to have higher prevalence estimates of gingivitis (Murray and McLeod, 1973; Svatun and Gjermo, 1977; Tesini, 1981; Forsberg et al., 1985; Vigild, 1985; Kendall, 1991). For example, Shapira et al. (1998) suggested that the increased prevalence of gingivitis among institutionalized individuals may be related to the mouth dryness associated with certain medications commonly used among individuals with MR living in such settings. Increased prevalence may also be related to the increased surveillance of gingivitis and poor oral hygiene among individuals living in institutions.

Other periodontal disease also has been shown to be more prevalent among individuals with MR, especially those living in institutions, compared with the general population. Sturmey and Hinds (1983) examined the dental hygiene of 26 U.S. adult residents with profound MR. They found that 33 percent had bruxism (wear on teeth due to grinding) and 20 percent lacked mastication (ability to close the mouth to chew food). In addition, Oilo et al. (1990) examined the wear of teeth among individuals with MR living in a Norwegian residential placement setting. They found that 5.3 percent of men and 2.8 percent of women had unacceptable tooth wear that required treatment compared with 1.2 percent in the general population.

DENTAL CONDITIONS AMONG SPECIFIC POPULATIONS

The dental health of two unique populations, including Special Olympics athletes and individuals with Down Syndrome, deserve special attention. Special Olympics Inc. (SOI) has taken an active interest in the oral health needs of individuals with MR (Shriver, 1998; Perlman, 2000). Consequently, several studies have reported the prevalence of oral health screenings at Special Olympics events (Feldman et al, 1997; White et al., 1998; SOI, 1999). Feldman et al. (1997), for example, documented the results of a screening program of Special Olympic athletes who participated in the New Jersey Special Olympic Games in 1996. They found that 6–8-year old children with MR had similar patterns of dental caries as children of the same age in the general population (56 percent versus 53 percent, respectively). Adolescent athletes 15 years and over, however, were less likely to have dental caries than adolescents in the general population (54 percent versus 78 percent, respectively). Further,

there appeared to be no difference between athletes aged 35 to 44 years and individuals of the same age in the general population who had tooth loss due to periodontal disease or dental caries (62 percent versus 69 percent, respectively). In contrast, athletes aged 65 years and older were more likely to have lost all of their natural teeth compared with their peers without MR (50 percent versus 36 percent, respectively). Additionally, preliminary evidence from SOI national and international administrative data collected in 2000 suggests that the overall prevalence of untreated dental decay among Special Olympic athletes in the U.S. is 24.6 percent, which is higher than the prevalence estimates in the U.S. general population (20.0 percent among school-aged children, 14.2 percent among working adults) (Kaste et al., 1996 and Winn et al., 1996 in SOI, 1999; SOI, 2000).

Further, the increased prevalence of gingivitis among Special Olympic athletes has been documented to be higher than that in the general population. Data from the 1996 New Jersey Special Olympic Games suggested that 68 percent of athletes aged 35–44 years had gingivitis compared with 42 percent in the general population (Feldman et al., 1997). In addition, recently compiled SOI administrative data from 1999 and 2000 found high overall prevalence estimates of gingivitis among Special Olympic athletes in the U.S. (42.0 percent), with estimates ranging from 23.5 percent to 73.0 percent (SOSS, 1999; SOI, 1999; SOI, 2000). In sum, SOI athletes tend to have an increased prevalence of untreated caries and gingivitis compared with the general population, while only older athletes have been shown to have an increased prevalence of tooth loss.

Individuals with Down Syndrome may be more susceptible to gingivitis and other periodontal diseases because they are thought to have underlying abnormal immunologic responses (Nespoli et al., 1993; Barr-Agholme et al., 1992 and Yavuzyilmaz et al., 1993 in Feldman et al., 1997; Beck et al., 1996). In a study of 120 children, Amano et al. (2000) found that children with Down Syndrome were more likely to have oral pathogens (or microorganisms capable of causing disease) associated with gingivitis compared with children without MR.

RATIONALE FOR INCREASED PREVALENCE

Since oral health is dependent on oral hygiene (U.S. DHHS, 2000b), the increased prevalence of oral health problems among individuals with MR may be related to their oral health habits (Waldman et al., 2000b). In fact, the oral hygiene among individuals with MR has been shown to be consistently poor compared with individuals in the general population (SOI, 1999). Among individuals with MR, those with moderate or severe MR have been found to brush their teeth more regularly than those with mild MR (Gizani et al. 1997). Those with moderate or severe MR, however, often have impaired physical coordination and cognitive sequencing skills that limit independence in task completion (Sturmey and Hinds, 1983). Consequently, they generally need assistance from caregivers to complete oral hygiene tasks.

Studies of oral health behavior also have been completed among athletes participating in Special Olympics Games. White et al. (1998) documented the results of a study of self-reported oral health habits of participants in the 1997 San Francisco Bay Area Special Olympics Special Smiles program. They found that 71.5 percent of athletes reported brushing their teeth at least once per day, 27.1 percent reported brushing their teeth two to six times per week and 0.8 percent reported brushing their teeth once per week. Estimates varied by age of participants. Younger athletes (9–20 year olds) were more likely to report brushing their teeth two to six times per week, while older athletes (21–49 year olds) were more likely to report brushing their teeth once per day. Even among this relatively high functioning population of individuals with MR, in which there is expected to be an over-reporting of positive health behaviors (SOI, 1999), over one-fourth did not maintain oral hygiene habits on a daily basis, providing evidence for the importance of instruction and reinforcement of daily oral hygiene among individuals with MR (Waldman et al., 2000c).

SUMMARY AND IMPLICATIONS

The available data suggest that the oral health of individuals with MR is poorer than that of their peers without MR. Although there are inconsistent findings on the prevalence of dental caries among individuals with MR compared with the general population, the majority of evidence suggests that individuals with MR have more untreated caries than those in the general population. Given that treatment of caries is a prevalent and accepted part of good health behavior for much of the world, this lack of treatment, even in developed countries, suggests problems in access to dental services.

Likewise, there is evidence that individuals with MR are likely to have a higher prevalence of gingivitis and other periodontal diseases compared with the general

population. The prevalence of these oral health conditions among individuals with MR, however, is dependent on age, etiology of MR and living situation. Older individuals with MR are at higher risk for poor oral health compared with younger individuals with MR and those in the general population. Further, individuals with Down Syndrome are more likely to have gingivitis compared with individuals in the general population. Additionally, although increased surveillance may influence the prevalence of disease detected, individuals living in institutions are at increased risk for gingivitis and other periodontal diseases compared with individuals in the general population.

As in the general population, good oral hygiene is an important measure to prevent oral diseases among individuals with MR. Interestingly, those with mild MR appear to have poorer oral hygiene when compared with those with moderate or severe MR, chiefly due to the increased supervision of those with more severe MR. This suggests that efforts to improve the oral hygiene of individuals with mild MR may be a particularly effective intervention.

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CHAPTER 6.—HEALTH SERVICES USE FOR INDIVIDUALS WITH MENTAL RETARDATION AND SUMMARY RECOMMENDATIONS

INTRODUCTION

Despite the high prevalence of health problems among individuals with MR, very little is known about the quantity and quality of services they receive to treat their health conditions. Similar to research on health status, most research conducted in this area relies on administrative-based data, taken from service providers, or small community registries, rather than large population-based data. Although individuals with MR commonly reside in the community and receive services there, the available data may not be representative of the overall population of community dwellers with MR.

In spite of the limitations of existing data, research indicates that most individuals with MR do not receive the services that their health conditions require. In fact, research on the access and quality of physical, mental, ocular and dental health care demonstrates that individuals with MR receive little medical care, compared with the general population (Howells, 1986; Wilson and Haire, 1990). Further, researchers have suggested that individuals with MR have four times more preventable mortality than individuals in the general population (Dupont and Mortenson, 1990 in Barr et al., 1999), suggesting that medical care may alter the health trajectories of individuals with MR.

Since the studies reviewed here are based primarily on health service data collected in the 1980s and early 1990s, they may not reflect current health services use, which has been shaped by the major health care reforms that took place in the 1990s. Given that individuals in the general population have indicated a reduction of preventive and specialty health care service use due to these new initiatives (Hurley et al., 1993 in Szilagyi, 1998), the service use documented in this chapter most likely overestimates the current use of services among individuals with MR.

In light of the health needs of individuals with MR described earlier in this report, the low health services utilization of this population certainly represents an under-utilization of care. To explain this phenomenon, this chapter reviews the

available research on access to health services for individuals with MR, using a framework based on a modified version of Andersen's behavioral model of access to care (Andersen and Davidson, 1996). In this framework, health service use is influenced by factors in the environment, as well as characteristics of individuals in the population. Environmental factors include health care delivery system characteristics (namely, the structure and integration of systems), the coordination of delivery systems (including provider factors) and the continuity and documentation of care. Individual characteristics are conceptualized in terms of predisposing factors (personal characteristics that existed prior to onset of disease), enabling resources (factors that permit an individual to get health care, such as health insurance) and need for care (either evaluated by professionals or perceived by the individual or caregiver).

Each of these factors can facilitate or impede health service utilization. After briefly reviewing the literature suggesting that health services are under-utilized by individuals with MR, this chapter focuses on the environmental factors and individual characteristics that serve as barriers to care for this population, and describes some efforts being made to overcome such constraints.

HEALTH CARE SERVICE UTILIZATION FOR INDIVIDUALS WITH MR

Despite the previously documented need for physical, mental, ocular and dental health services for individuals with MR, adequate services in this population are not frequently utilized. Individuals with MR, for example, have been shown to consult general practitioners less than others with special needs, including those less than 5 years of age or those 75 years of age and older (Jones and Kerr, 1997). Similarly, those with both mental health and MR diagnoses may be one of the most underserved populations in the U.S. (Reiss et al., 1982). Services for the dually diagnosed have been found to be deficient in availability, accessibility and adequacy in the U.S. (Jacobson, 1998), and a great need to increase access to special psychiatric services for those with MR has been documented (Menolascino et al., 1986; Reid, 1972, Hucker et al., 1979, Wright, 1982 and Sovner, 1986 in Day, 1994).

Specifically, studies suggest that between 50 percent and 80 percent of individuals with MR have had contact with their primary care provider in the previous 12 months (Singer et al., 1986; Howells, 1986; Wilson and Haire, 1990; Howells, 1991; Lennox and Kerr, 1997; Piachaud et al., 1998). Among those who do seek medical care for physical health conditions, researchers have found that, on average, those with MR have 2.7 medical visits per year, which is similar to the general population of men (3.0 visits per year), but less than the general population of women (5.0 visits per year) and populations of vulnerable groups such as children and the elderly (5.7 visits per year) (Wilson and Haire, 1990).

Moreover, small community-based studies have found that only 30 percent to 47 percent of individuals with MR receive care from specialists (Singer et al., 1986; Allison et al., 2000; Piachaud et al., 1998), despite the finding in another small community study by Minihan (1986) that 92 percent of individuals with MR had medical needs that required specialty medical care. Tonge (1999), for instance, found that while 41 percent of young people with developmental disabilities had disruptive antisocial behavior, only 10 percent received specialty mental health services. Similarly, among adults with moderate to profound MR in England, 75 percent of those with psychiatric illnesses have been found to receive no treatment (Cooper, 1997).

Further, referrals to psychiatric services tend to vary with severity of MR, with referrals decreasing as the severity of disability increases and functioning decreases (Borthwick-Duffy and Eyman, 1990; Driessen et al., 1997). Other patient characteristics have been associated with referral rates as well. Older individuals living alone, for instance, are more likely to receive psychiatric treatment than younger individuals living with others (Driessen et al., 1997).

Similarly, despite the clear benefits to early and frequent visual and oral assessments, research shows that individuals with MR receive less appropriate ocular and dental services than those without MR (Levy, 1984; Haavio, 1995). For example, at the SOI 1999 World Summer Games, the Special Olympics Opening Eyes Vision Health Program found that 32 percent of athletes had never had an eye exam, and almost 20 percent had not had their last eye exam within the two previous years (SOI, 1999a). Further, a study of Scottish hospitals indicated that 56 percent of patients with disabilities had no record of any past eye examination, and a disproportionate number of those who did have eye exams had only mild or moderate disabilities (McCulloch et al., 1996).

In addition, although Piachard et al. (1998) reported that 92 percent of individuals with Down Syndrome living in a borough of London used dental services in the past year, most researchers have documented that only 70.1 percent to 82.0 percent

of individuals with MR use dental care services each year (Feldman et al., 1997; Manley and Pahl 1989; Allison 2000; Cumella et al., 2000). For example, in a Special Olympics, Special Smiles screening program at the 1996 New Jersey summer games, Feldman et al. (1997) found that 70.1 percent of athletes saw a dentist in the past year and an additional 8.2 percent of athletes saw a dentist within the last two years. Additionally, screening data from the 1999 Special Olympics Games in North Carolina suggests that 41.8 percent of athletes required dental care beyond routine cleaning (SOI, 1999b).

The quality of health services received by those individuals with MR who do access care, however, may not be optimal. For example, despite the fact that individuals with MR have an increased prevalence of certain health conditions, such as thyroid disease, diabetes and obesity, many of these conditions are not addressed by primary care providers (Howells, 1986; Wilson and Haire, 1990; Jones and Kerr, 1997). Jones and Kerr (1997), in fact, found that 50 percent of individuals with Down Syndrome from five general practices in Wales never had a thyroid screening test. In addition, despite the establishment of screening tools and low threshold referral systems for the diagnosis and management of impairments, several researchers have noted that individuals with MR do not receive preventive or health maintenance activities, such as annual health screenings (Ineichen and Russell, 1987; Beange and Bauman, 1990a; Wilson and Haire 1990; Kerr et al., 1996; Jones and Kerr, 1997; Evenhuis et al., 1997).

Similarly, individuals with MR who receive mental health services often do not receive quality care. As discussed in a previous chapter, many mental health professionals lack training in providing care to individuals with MR (Moss, 1999). Given that individuals in this population may present with atypical symptoms (King, 1993 in Verhoeven and Tuinier, 1999; Stavrakaki, 1999, Meins,1995 in Verhoeven and Tuinier, 1999; Verhoeven and Tuinier, 1999) and have difficulties communicating with providers (Sovner, 1986 in Crews et al., 1994; Sturmey, 1999), the care they receive from inexperienced professionals may be compromised.

In addition, both the detection and the treatment of ocular anomalies are often inadequate among individuals with MR. This is particularly important because many ocular deficits are correctable. In fact, Woodruff found that 49 percent of institutionalized individuals with MR had a correctable spherical refractive error, and 37 percent had a correctable astigmatism (Woodruff, 1980). Even among individuals who receive correction, however, a study of the 1995 Special Olympics World Summer Games found that many athletes were not using an adequate lens (Block et al., 1997). Similarly, McCulloch et al. (1996) found that 38 percent of Scottish hospital patients with disabilities did not have appropriate correction of refractive errors.

Early diagnosis and frequent assessments and intervention, however, can prevent the long-term effects of this increased prevalence of uncorrected visual anomalies (Woodruff, 1977; Woodruff et al., 1980; Bartlett, 1987). For instance, since the onset of most cases of strabismus is before five years of age, early intervention may prevent the loss of visual efficiency over time. Further, studies have shown that glasses are generally utilized by individuals for whom they are prescribed (Warburg, 1964 and Warburg 1970 in Jacobson, 1988; Jacobson, 1988). For example, Jacobson (1988) found that after 16–18 months, 74 percent of institutionalized individuals were still wearing their prescribed glasses, and Gardiner (1965) reports that 50 percent of those for whom glasses were prescribed in a school for children with MR were wearing the glasses after 3 months. This high utilization rate indicates the helpfulness of corrective lenses. In fact, correcting poor vision with appropriate glasses can have an enormous impact on children's functioning. In general, individuals receiving and using appropriate glasses show improvements not only in reading, writing and fine motor skills, but also in other areas, such as social interactions, challenging behavior and general achievement (Bader and Woodruff, 1980 in Polcar, 1983; Levy, 1984; Bartlett, 1987; Ronis, 1989; McCulloch et al., 1996; Evenhuis and Nagtzaam, 1997). Kuroda et al (1987), for example, showed that Japanese children with MR became more active and lively after using appropriate glasses.

Additionally, individuals with MR do not receive adequate dental care, despite the findings that they have poor oral health. One preventive measure against dental decay is the use of dental sealants. Recognizing the importance of this measure of preventive dental care, the U.S. Surgeon General set a target of 50 percent of school-children to receive dental sealants by the year 2000. To date, only 23 percent of 8-year old children in the U.S. have received dental sealants, but fewer children with MR have received such care (CDC, 2000; SOI, 1999b). Feldman et al. (1997) found that 14 percent of 1996 New Jersey Special Olympic athletes aged 8 years old had received a protective sealant, and 16 percent of adolescent athletes had received a protective sealant. Similarly, data from 32 Special Olympic Games indicate

that only 13.9 percent of Special Olympic athletes in the United States (including both adults and children) have dental sealants (SOI, 2000).

BARRIERS TO CARE

There are numerous reasons, including both environmental factors and individual characteristics, why the health needs of individuals with MR are not being met. Both nationally and internationally, current systems of health care rely on an individual's ability to recognize the need for care, seek care when necessary and, to some extent, coordinate the provision of care. Even in Western Europe, where systems of care are designed to be coordinated, individuals are commonly left to manage their own care. Those with MR, however, often lack the ability to recognize health problems, and when they do identify the need for services, many environmental and individual barriers prevent them from receiving necessary care (Wilson and Haire, 1990).

Environmental Factors

The way in which health care is organized creates an environment that can either increase or impede access to services. In the past, individuals with MR received health services through contained systems of care within the institutions where they lived (Minihan, 1986). Deinstitutionalization, however, has forced individuals with MR to rely on community-based health providers for their health service needs (Garrard, 1982; Minihan, 1986; Waldman and Perlman, 2000). In response to this reliance, communities have developed different service delivery models to care for individuals with MR, largely based on the structure of the country's pre-existing health system for the general population. Health systems in the U.S. and Western Europe, for example, vary in the degree to which service sectors are financially integrated and bureaucratically organized, which has a direct impact on the coordination, continuity and documentation of care. In turn, these aspects of health services influence both access to and the quality of health care services for individuals with MR.

Health Care Delivery System

In the U.S., individual medical care (e.g., physical, mental, ocular and dental health care services), community preventive health services (e.g., immunization and screening programs) and health-related social supports (e.g., respite care and crisis intervention through social service agencies) (Halfon et al., 1996) are separate entities that are operated through different agencies. As a result, distinct sectors of care with different agendas, philosophies and funding streams have developed, leading to an overall fragmentation of health care for Americans (Halfon et al., 1996; Savino et al., 1973). In fact, few American communities have comprehensive health care that integrates services both between and within each sector of care (Davidson et al., 1995).

In an attempt to decrease the fragmentation of services and contain costs, health care financing recently has been reorganized into various managed care arrangements. Under managed care, the primary point of entry into the U.S. health care system is the primary care physician (Birenbaum, 1995 in Tyler et al., 1999), who has been designated the gatekeeper and, thus, to some extent the coordinator of care between and within all sectors (Kastner, 1991; Birenbaum, 1995). In addition to gatekeeping, managed care plans use utilization management and practice guidelines to encourage primary care service utilization and discourage the use of preventive care and specialty services. In fact, in many states, specialty care services such as dental care are not covered by state Medicaid managed care plans (Waldman and Perlman, 2000). Thus, managed care has resulted in a decreased access to preventive and specialty health services among individuals in the general population. Under the care of health maintenance organizations (HMOs), for example, individuals generally must endure longer waiting periods for care and a limited use of specialist providers (Kastner, 1991). Further, as HMOs have increasingly gained responsibility in the behavioral health sector, concerns regarding the access of individuals to psychiatric services has increased (Jacobson, 1998).

Like the general population, many individuals with MR who receive Medicaid have been transitioned into managed care plans (Kastner et al., 1997 in Walsh and Kastner, 1999; Hemp and Braddock, 1998). The current system of managed care, however, is particularly detrimental for individuals with MR, because these individuals have unique health care needs that often require coordination by providers experienced with MR (Ashbaugh and Smith, 1996; Birenbaum and Cohen, 1998). As discussed below, however, coordination of care or case management by the primary care provider is frequently ineffective in this population because these providers do

not view themselves as having the primary responsibility for the health care of individuals with MR (Barr et al., 1999).

In contrast to the fragmented health care system found in the U.S., Australian and Western European countries, such as Sweden, France and Great Britain, have opted for more integrated health service systems, in which health care is an insured and guaranteed consumer good or service financed through private insurers or state-supported systems. Since health, developmental and social service sectors of care have similar funding streams, and are organized primarily by local health authorities that track population needs (Rodwin, 1999), the coordination of health services may be less fragmented in these systems than in sector-based health care systems. Unlike the sector-based system of care, individuals with MR in more integrated health care systems rely on the advice of two MR teams (primary care and community), which are designed to liaise available health and social community resources with the needs of individuals with MR (Griffin, 1989; Lennox and Kerr, 1997). Since the general practitioner is the most frequent provider of health care for individuals with MR, he or she is an essential part of the primary care team (Howells, 1991; Lennox and Kerr, 1997). Community teams, in countries such as the United Kingdom (U.K.), provide disabled individuals with social service needs assessments, from which individualized care packages are devised. Multidisciplinary teams in London, in fact, currently plan the management of the dually diagnosed, integrating specialty psychiatric services and generic mental health services (Golding, 1982; Bouras et al., 1994).

In theory, these integrated systems of care are better able to manage the care of individuals with MR than sector-based systems of care. In practice, however, these Australian and European systems of care have been shown to fall short of providing adequate health care for individuals with MR. (Shapiro, 1974; Rodgers, 1994 in Bond et al., 1997; Cooper, 1997). Using one region in the U.K. as an example, Myers (1982) suggested that inconsistencies in the philosophies and policies of the health and local authorities prevents true integration of care, and consequently results in poor overall health care of individuals with MR.

Coordination of Care through Primary Care Providers

Part of the difficulty in coordinating care between sectors is due to the assumption that the primary care provider will be the gatekeeper of care. Primary care providers, however, tend to avoid the role of care manager for individuals with MR because of a lack of training, financial disincentives and time constraints. For example, national and international research suggests that primary care providers often lack training on how to interact with individuals with MR, as well as the specialized medical, preventive and social service needs of individuals with MR and the resources available to this population (Fremont, 1968; Shonkoff et al., 1979; AACAP, 1999; Garrard, 1982; Greenhalgh 1994 in Barr et al., 1997; Davidson et al., 1995; Davidson, 1995; Martin et al., 1997; AACAP, 1999; Allison et al., 2000). In a study of family practice medical programs in the U.S., for example, Tyler et al. (1999) found that 84 percent of programs that responded provided residents with one or more experiences with individuals with MR and 60 percent of programs instructed residents on MR. Additionally, providers indicate a need to broaden their training (Holt and Huntley, 1973; Dobos Jr. et al., 1994; Lennox and Chaplin, 1996; Lennox et al., 1997). For example, in a study of general practitioners in Australia, Lennox et al. (1997) found that 69 percent of providers had experience with individuals with MR, but 93 percent of general practitioners felt that they would benefit from additional training on MR. Similarly, Lennox and Chaplin (1996) found that 79 percent of psychiatrists surveyed stated that they had not received sufficient training in the general or behavioral management of those with dual diagnoses.

Dental schools have also reported minimal exposure of dental students to individuals with MR (Waldman and Perlman, 2000). Waldman and Perlman (1997) reported the results of a recent study that found that 47 percent of dental schools had eight or fewer didactic hours on the treatment of developmental disabilities and 65 percent of dental schools had 10 or fewer hours on clinical activities associated with individuals with developmental disabilities. Similarly, a study of the dental health providers who volunteered to provide dental screenings at the 1996 Special Olympic Games in Massachusetts found that 75 percent of dental health students and professionals had never worked with individuals with MR prior to the Games (Perlman and Broder, 1996). Not surprisingly, then, Perlman and Broder (1996) found that prior to the Games, only 45.9 percent of providers reported that they were very comfortable with individuals with MR, while 29.8 percent reported that they were somewhat comfortable and 16.2 percent reported neutral feelings about individuals with MR.

This lack of training and experience, then, may influence providers' willingness to provide treatment to individuals with MR as well as influence their attitudes and beliefs about individuals with MR. Waldman et al. (1999), for example, report that only 29 percent of dentists nationally participated in Medicaid managed care, the predominant health insurance for individuals with MR. Additionally, many authors have noted that health care providers have negative attitudes and stereotypes about individuals with MR and their ability to maintain their health status (Garrard 1982; Murdoch et al., 1984 in Lennox et al., 1997; Barker and Howells, 1990; Minihan, 1993; Greenhalgh 1994 in Barr et al., 1999; Martin et al., 1997; Lennox et al., 1997). Lennox and Chaplin (1996), for example, found that 39 percent of psychiatrists surveyed would prefer not to treat people with both MR and mental health conditions. Beange (1996) points out that some doctors are concerned about disrupting their other patients if individuals with MR are kept waiting too long in the reception area. Further, Garrard (1982) notes that physicians make value judgments about the worth of individuals with MR in making diagnostic and treatment decisions, suggesting that physicians with negative attitudes may withhold treatment. Surveys of providers, in fact, have suggested that physicians have lower expectations and more pessimistic views on the roles of individuals with MR than other professionals and family members (Siperstein et al., 1994; Nursery et al., 1990 in Lennox and Kerr, 1997). As a result of these attitudes, many providers are reluctant to spend time managing the care of individuals with MR. Moreover, due to certain stereotypes, providers that do assume the role of coordinator may not refer these individuals to needed specialty care (Fischler and Tancer, 1984; Goodman and Cecil, 1987; Kelly and Menolascino, 1975 in Minihan et al., 1993; Bickley 1990; Minihan et al. 1993; Burtner and Dicks, 1994 in Perlman and Broder 1996).

Further, research indicates that present health care systems do not adequately reimburse providers (including dental) for the care given to individuals with MR, creating a disincentive to treat these individuals (Waldman et al., 1999). In fact, Hemp and Braddock (1998) documented that the majority of Medicaid managed care programs for individuals with disabilities use a risk- based plan in which primary care physicians are responsible for costs that exceed standard payments. Additionally, under most health systems, providers are reimbursed at the same rate for all patients regardless of case complexity, yet treatment consultation time is greater for individuals with MR than individuals in the general population (Lennox et al., 1997). As a result, when an individual with MR has co-existing conditions (Bouras and Szymanski, 1997), the primary care provider and another provider may each view the other as taking responsibility for the management of care. This diffusion of responsibility (Fletcher et al., 1999) can be particularly problematic for dually diagnosed individuals, when care is sought from both a primary care physician and a psychiatrist (Reiss, 1994 in Fletcher et al., 1999). Since it is generally not to the financial advantage of either the mental health or the physical health care system to take primary responsibility for a patient's needs, neither may want to establish the "primary diagnosis" (Menolascino et al., 1986), which would indicate responsibility for coordination of care.

Additionally, the U.S. managed health care system is structured so that primary care physicians generally lack the time necessary to devote to the complex medical, preventive and social needs of individuals with MR (Department of Health, 1995; Lennox et al., 1997), making providers an overburdened and inefficient source of case management. Rather than providing comprehensive case management, then, primary care providers focus on the medical needs of individuals with MR with which they are most familiar, often overlooking or not examining important preventative and social needs (Beange and Bauman, 1990a; Wilson and Haire, 1990; Councilman, 1999).

As a result of poor coordination between service sectors, then, individuals with MR often have limited access to certain services, which leads to a poor quality of overall health care. In addition, researchers have documented that when individuals are referred for specialty care, the collaboration between primary care providers and specialists about the health of individual patients is limited (Cumella et al., 1992; Lennox and Chaplin 1995; Lennox and Chaplin, 1996 in Lennox et al,. 1997).

Continuity and Documentation of Care

Even when individuals with MR are able to access care, other organizational factors, such as a lack of continuity of care and insufficient documentation present barriers to the quality of care received by this population (Parker and Hirst, 1987; Haavio 1995; Crocker et al., 1987; Greenhalgh 1994 in Barr et al., 1999; Martin et al., 1997 in Barr et al., 1999; Cumella et al., 1992; Lennox and Chaplin 1995; Lennox and Chaplin, 1996 in Lennox et al., 1997; Wilson 1992 in Perlman and Broder 1996; Garrard, 1982; Crocker, 1988, Beange and Bauman, 1990b; Minihan and

Dean, 1990, Minihan et al., 1993; Benage, 1996 in Lennox et al., 1997; Waldman and Perlman, 1997; Gordon et al., 1998). Health care for individuals with MR, for instance, lacks a continuity of providers. This was exemplified by a small study of individuals with MR living in the community, which found that only 17.7 percent of individuals had seen the same physician or been to the same clinic twice (Edgerton et al., 1994). The majority of individuals with MR did not have a regular source of care. Concern has also been expressed about the continuity of care when individuals with MR make transitions in their life, such as moving from pediatric to adult medical care (Parker and Hirst, 1987). Because individuals with MR have difficulty adjusting to unfamiliar surroundings and thrive in structured routines, consistent and familiar providers are particularly important to the treatment of these individuals.

Further, researchers have noted that access to health care is compromised for individuals with MR because there are insufficient tracking systems to inform individuals with MR when it is time for a routine checkup (Haavio, 1995). Documentation problems also are evident in the lack of available medical records recording case histories of individuals with MR (Crocker et al., 1987; Greenhalgh 1994; Martin et al., 1997 in Barr et al., 1999). In a study by Lennox et al. (1997), 89 percent of general practitioners agreed with the statement that they had difficulty obtaining access to the medical history of a patient with MR. Despite the global emphasis on mainstreaming and normalization, then, both nationally and internationally, most community health care systems have been unprepaed to meet the health needs of individuals with MR outlined earlier in this report (Garrard, 1982; Minihan, 1986; Howells, 1991; Howells, 1996; Minihan and Dean, 1990; Hand and Reid, 1996; Birenbarum, 1995 in Tyler and Bourguet, 1997).

Individual Characteristics

Many characteristics of those with MR may prevent these individuals from receiving adequate health care services. While predisposing factors and the prevalence of enabling resources might hinder the ability to seek and receive quality health care once need has been established, the inability to identify the need for care may prevent individuals from ever even recognizing that such care is necessary.

Predisposing Factors

Individuals with MR may be reluctant to seek medical care because they are frightened of new surroundings and treatment procedures (Gordon et al., 1998; Evenhuis et al., 2000). In a survey of members of the Association of Retarded Citizens, for example, Gordon et al. (1998) found that 27.9 percent of individuals with MR were anxious about dental visits.

Once health care is obtained, several characteristics of individuals with MR may negatively affect the quality of care received. These constraints include poor communication between individuals with MR and providers, physical and behavioral difficulties in treating individuals with MR and an inability of individuals with MR to understand the importance of adherence to treatment regimens. Most researchers, clinicians and patients recognize that communication between patients and medical providers is an essential component of quality care. Poor communication, however, is a significant barrier to quality health care for individuals with MR (Diamond, 1982; Howells, 1986; Barker and Howells, 1990; Bickley, 1990; Beange and Bauman, 1990b; Cumella et al., 1992; Minihan et al., 1993; Beange et al. 1995; Beange, 1996; Lennox et al., 1997). Because many individuals with MR have limited communication skills, providers must rely on caregivers' reports and observations to obtain accurate medical histories, to understand the health complaints of individuals with MR, and to communicate treatment regimens (Beange, 1996; Lennox and Kerr, 1997; Evenhuis et al., 2000).

Physical and behavioral impairments can also impede individuals with MR from receiving adequate medical care (Gardiner, 1965; Mayer et al., 1983; Gnadt and Wesson, 1992; Haavio, 1995). Individuals with MR may have comorbid neurological conditions, which may be heightened in unfamiliar situations, and thus make sitting through and cooperating with medical examinations and procedures difficult. This is exemplified in the problems of dental care delivery described by the Missouri Elks Mobile Dental Program (Dane, 1990). Dane (1990) notes that individuals with athetoid cerebral palsy, who have an increase in involuntary movements during stressful situations, often require restraints or general anesthesia to receive dental treatment. In addition, women with cerebral palsy with and without MR have been noted to have difficulty obtaining dental and gynecologic care as a result of neurological impairments (Turk et al., 1997 in Evenhuis et al., 2000).

Individuals with MR also may have difficulty adhering to treatment regimens (Lennox et al., 1997; Webb and Rodgers, 1999). As a direct result of their cognitive

impairments, individuals with MR frequently have difficulty understanding the benefits to treatment adherence. Additionally, perhaps due to the lack of continuity of care mentioned above, individuals with MR often do not develop a therapeutic relationship with medical providers, which would increase the likelihood of adhering to a treatment regimen.

Enabling Resources

Individual resources, such as health insurance,can also influence access to care. Although individuals with MR are entitled to Social Security Disability Income (SSDI) and Medicaid, not everyone in this population utilizes these benefits, and thus many face financial barriers to care. Dental care, for example, is not covered by most state Medicaid plans, and in those states where dental care is covered, reimbursement rates are low (Waldman and Perlman, 2000; Waldman and Swerdloff, 1999). Further, in a national study, Birenbaum and Cohen (1993) reported that 4 percent of those with severe or profound MR had no insurance coverage. Not surprisingly, the percentage of the uninsured who did not visit a physician in the 12-month study period was three times higher than that for insured individuals. Further, 20 percent of the sample parents of children with severe or profound mental retardation had experienced refusals or limitations in the health insurance they could purchase for their child, and about 15 percent of those with private insurance had policies that specifically excluded coverage for some of the child's health care. Consequently, the families of these children spent an average of 7 percent of their income on health care, and 10 percent spent over 15 percent of their total income on these services. For those with limited incomes, who are not receiving government benefits, health care costs can be an insurmountable barrier to services.

Need for Care

As documented previously in this report, individuals in this population have many health needs. Individuals with MR, however, often have difficulty determining when they are in need of medical assistance and rely heavily on caregivers to recognize signs of health problems or to schedule routine health care appointments (Wilson and Haire, 1990; Lennox et al., 1997; Webb and Rodgers, 1999). Caregivers, though, have been shown to have a poor understanding of symptoms and are often reluctant to seek care for individuals with MR, particularly when their health problems seem mild compared with their more complex medical conditions (Lennox and Kerr, 1997; Lennox et al, 1997). Additionally, perhaps because of a low availability of respite care, which can provide important support to caregivers, high caregiver turnover can prevent caregivers from recognizing changes in the health of individuals with MR or knowing the past medical histories of individuals with MR (Lennox et al., 1997; Hoare et al., 1998; Waldman and Perlman, 2000).

EFFORTS TO ADDRESS UNMET NEED

In response to the barriers faced by individuals with MR to receive quality health care services, many have suggested changes in the primary care physician's role in the treatment of individuals with MR (Pearson, 1968; Fremont, 1968; Adams, 1972; Merker and Wernsing, 1984; Crocker et al., 1987; Councilman, 1999). Despite physicians' general reluctance to treat those with MR, some advocates insist that primary care providers should assume responsibility for the health management of individuals with MR over a long period of time. According to these proponents, providers, including physicians and nurse practitioners, should make medical and preventive care readily available, coordinate referrals to specialty care (including dental), educate family members or caregivers and coordinate with education and social service agencies.

Further, in order to address the lack of care for the dually diagnosed, some have suggested that clinicians provide services based on need, rather than primary diagnosis (Fletcher et al., 1999), thereby avoiding the diffusion of responsibility. Others have advocated that community mental health centers be opened to the dually diagnosed, who often have no place else to go (Reiss et al., 1990), and some have indicated that psychiatrists should be responsible for the assessment of those with MR (Reid, 1980), or at least take the role of educating physicians (McCreary, 1991).

In addition, countries and communities have responded differently to the unmet health care needs of individuals with MR. Some countries have actively evaluated the care of individuals with MR and provided guidance to local communities in service delivery for individuals with MR. For example, in the U.K., the Department of Health examined the health service needs and adequacy of the health system for individuals with MR in the 1995 report entitled, *Health of the Nation: Strategy for People with Learning Disabilities* (Department of Health, 1995). Further, general practitioners in the U.K. provided guidance to the care of individuals with MR with

an Occasional Paper entitled, *Care of People with Mental Handicap* (Barker and Howells, 1990 in Howells, 1991).

In the U.S., a group of physicians organized the Sterling D. Garrard symposium on community health services for individuals with MR in 1986. From this workshop, Crocker et al. (1987) outlined ten essential components in health services for individuals with MR, including multiple options for the delivery of health care, usual source of care through a primary care provider, health care networks, coordination of care, comprehensive personal medical record, standards for health service delivery, adequate reimbursement for providers, training of providers, and health service research and evaluation.

Further, recognizing that the U.S. health system is not designed to meet the unique health care needs of individuals with MR, demonstration projects and research programs have been developed that use a more integrated health care model either through case management or multidisciplinary teams (Perrin et al., 1972; Fujimoto et al., 1978; Cole, 1987; Schor et al., 1981; Griswold et al., 1987; Tesini, 1987; Ziring et al., 1987; Ziring et al., 1988; Chicoine et al., 1994; Criscione et al., 1995; Davidson et al., 1995; Pulcini and Howard, 1997; Braddock and Hemp, 1997). Despite the published research suggesting that care coordination is the key to effective health care service for individuals with MR (Gregg, 1967; Grossman, 1968; Davidson et al., 1995; Walsh et al., 1997; Evenhuis et al., 2000), however, no widespread integrated systems of care have been created for individuals with MR in the U.S.

In part, this may be because the U.S. government has not shown adequate leadership in the effort to increase health care utilization among individuals with MR. Most government resources focus on the prevention of MR, deinstitutionalization, and housing, education and employment of individuals with MR. Little information is even available at the federal level on the quality of health care and service utilization of individuals with MR.

SUMMARY AND IMPLICATIONS

Similar to studies on the prevalence of MR and other health conditions, research efforts on health care service use by individuals with MR are scarce. Studies that do address service use in this population tend to focus on non-representative samples of the population, and indicate that individuals with MR do not receive adequate physical, mental, ocular or dental health care.

Many barriers to care have been cited to explain the low utilization of services and poor quality of care among individuals with MR. The most compelling constraints include uncoordinated systems of health care, providers' lack of training and caregivers' lack of knowledge and abilities. Despite the influx of managed care in the U.S., American health care remains fragmented and difficult to access. Further, although Western Europe is thought to have a more centralized system of care, health care systems abroad have been shown to have problems with care coordination as well.

Within these fragmented systems of care, primary health care providers in the U.S. have been given the responsibility to coordinate care for individuals with MR. As a result of insufficient training, however, health care providers often resist treating such patients and are ineffective coordinators of care. Thus, individuals with MR must navigate themselves through a disorganized and disjointed system of care, without assistance in the overall management of the complex services essential to a comprehensive regimen of care. Health care for those with MR, however, cannot be maintained unless and until providers are willing and able to manage and treat the health care of this population.

Further, caregivers play a large role in ensuring that those with MR receive proper health care. Despite good intentions, however, caregivers often are not able to recognize when health care is needed, are not knowledgeable enough to access adequate care, and do not have adequate resources to relieve caregiver burden.

When individuals with MR were deinstitutionalized and entered the community, the responsibility of providing health care to this population entered the community as well. In order to meet accepted standards for adequate health care for these individuals, the health care system will need to adapt to their diverse needs. Until that happens, however, providers and caregivers can play a large role in improving the health care of individuals with MR.

SUMMARY RECOMMENDATIONS

Individuals with MR are susceptible to many of the same health conditions as individuals in the general population, but may experience more access and quality of care challenges than individuals without MR. Although this report identified a con-

siderable volume of studies on the health of individuals with MR, most research efforts in this area are laden with methodological constraints. Consequently, to remediate the problems identified in this report, we recommend the following actions:

Policy

1. The U.S. federal government and national organizations must take a leadership role in turning the nation's attention towards the health of individuals with MR. For example, the President's Committee on Mental Retardation or the U.S. Surgeon General should produce a periodic report detailing the current health status and needs of individuals with MR. Agencies, such as the Arc, can play a large role in lobbying for such efforts.

2. Presently, many individuals with MR may not be receiving health services because they are under-insured. To ensure that individuals with MR can and do access necessary services, eligibility for publically funded health insurance programs (e.g., SSDI, CHIP and Medicaid) must be determined, and qualified individuals must be enrolled.

3. Public schools are provided with a great opportunity to improve the health of children with MR. By law, these schools are required to provide an Individualized Education Program (IEP) to every child with MR. As part of each IEP, the health needs of such children should be assessed and appropriate services accessed.

System of Care

4. Individual providers are often relied on to manage the health care of individuals with MR. Because of the fragmented delivery of care in the U.S., health care payors must reimburse for integrated service teams with case managers, capable of managing all aspects of care over a long period of time.

5. Currently, the health care system provides financial disincentives to work with patients with MR. The present reimbursement system must be modified to encourage providers to treat individuals with MR, and financially reimburse those who choose to work with this population.

6. Providers are often ill prepared to treat individuals with MR because patients may not be capable of describing their medical histories, and the medical record system is not equipped to provide such information. The record system is in need of reform in order to address the lack of continuity of care received by this population. One way to do this would be to initiate a health passport system, where individuals with MR and their caregivers keep an ongoing record of their care, and are able to present it to their providers at each visit.

Clinical Care

7. One reason that the health care system does not adequately provide care to individuals with MR is that providers (e.g., physicians, nurses, psychologists, opthamologists and dentists) do not feel equipped to treat them. The curricula and training for all health care providers should be reviewed and updated to include specific education on MR. This should include not only classroom hours, but also clinical experience with this population.

8. Guidelines help to ensure the quality of care and to raise providers' confidence that they are providing appropriate care. Specific screening and health supervision guidelines should be developed for individuals with MR, addressing their special health care needs.

Individuals with MR and Their Caregivers

9. Given the shortcomings of our present health care system, caregivers are often relied on to coordinate the care of their charges. Caregivers should be provided with training, in order to help them understand how to recognize health problems and access appropriate care. Organizations such as the Arc should be enlisted as partners in the development of educational programs for caregivers.

10. The viewpoint of individuals with MR is lacking in the discussion of the health needs of this population. Individuals with MR should be given the opportunity (e.g., in focus groups) to express their views about the health care system and ways to improve access to quality care.

11. Individuals with MR should be educated about disease prevention, recognition of symptoms of health conditions and health maintenance. Developmentally appropriate teaching materials should be utilized with this population to promote self-sufficiency and human dignity.

Research

12. Because of the inconsistent definitions of MR used to identify individuals in this population, it is difficult to estimate accurately the number of people with MR,

the health conditions that this population endures, or the individuals eligible for special services. The U.S. federal government must take the lead in developing a valid and reliable definition of MR, to be used for both research purposes and service eligibility criteria for this population.

13. Population-based data are necessary to determine accurately the health needs of the whole population of individuals with MR. These data can be obtained by reinstituting the National Health Interview Survey (NHIS) question regarding MR that was removed in 1988. Consideration also should be given to the development of a national registry of individuals with MR to track their health and health care issues.

When individuals with MR were deinstitutionalized and entered the community, providing health services for this population was not adequately planned. Individuals with MR, however, have many special health care needs, which increase in prevalence as they age. In order to improve the quality of life for individuals with MR, health care, among other, services, must adequately and appropriately be provided to this population.

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ADDITIONAL PREPARED STATEMENTS

Senator STEVENS. The subcommittee has received two prepared statements that will be placed in the record.

[The statements follows:]

PREPARED STATEMENT OF JANE V. WHITE, PRESIDENT, AMERICAN DIETETIC ASSOCIATION

The American Dietetic Association (ADA) is pleased to submit written testimony on the health status and needs of persons with mental retardation. With nearly 70,000 members, ADA is the world's largest organization of food and nutrition professionals. Our members are dedicated to serving the public through the promotion of optimal nutritional health and well being.

It is the position of the American Dietetic Association that program planning for persons with mental retardation should include comprehensive nutrition services as part of the health care, vocational and other programming offered to this population. Individuals with mental retardation live in and work in the community. They face the same problems (i.e. poverty, employment challenges and access to quality health care) that others in the community face. However, they have the additional challenge of mild to severe cognitive limitation. Because they may not appreciate the full implication that poor health practices have on health and well being, they are at increased risk for receiving inadequate services which can negatively impact health status throughout life.

Changes in services offered to this population have limited the scope of and availability of nutrition services, which vary widely throughout the nation. With the shift to a managed care environment and movement from institutional to community settings, the individual with mental retardation often is left without the support system to accomplish simple tasks such as meal planning and the preparation of nutritious meals for themselves.

NUTRITION CONCERNS

Mental retardation may be the result of identified etiologies (e.g. chromosomal abnormalities, anomalies, inherited metabolic disorders, or specific syndromes) or may be associated with a diagnosed disease or condition. Occasionally, persons may have two or more conditions such as Downs syndrome and congenital heart disease. Selected disabilities associated with frequently reported nutrition problems are noted in the table that appears on page 2.

NUTRITION PROBLEMS ASSOCIATED WITH SELECTED DISABILITIES

Disability	Altered growth, underweight, obesity	Altered energy needs	Altered nutrient needs, nutrient deficient	Constipation/ diarrhea	Feeding problems	Drug-nutrient interactions
Downs Syndrome	X	X	X	X	X	
Prader-Willi Syndrome	X	X			X	
Seizure Disorder			X			X
Mental retardation of unknown etiology	X	X		X	X	X

Healthy People 2010, the federal government's health objectives for the nation, notes the concerns about the nutritional status of persons with disabilities, including physical, mental, and developmental disabilities, in community settings. The nu-

trition objectives in Healthy People 2010 contain indicators for the population with disabilities. However, in some key areas the data on healthy food consumption and use of nutrition assistance programs (i.e. food stamps) is not available. The data is insufficient to accurately make projections and evaluate the status of the food assistance needs of this population on a national basis.

Overweight and obesity have reached epidemic proportions in the United States. Individuals with mental retardation are at higher risk for obesity than the population as whole. Nutrition screening conducted by ADA members during the 1999 Special Olympics World Summer Games revealed that 53 percent of American athletes participating in these games had a body mass index (BMI) that indicated overweight and 33 percent had a BMI that indicated obesity and were at risk for significant health problems. BMI is a screening tool to determine nutrition status and overall health and correlates with measures of subcutaneous and total body fat.

Data reported from the New Jersey 2000 Special Olympics indicated that 33.5 percent of the adults participating in these games had a BMI that indicated overweight and 32.6 percent had a BMI that indicated obesity. In the same survey, almost two-thirds (64.4 percent) of the participating children screened were overweight. The children who were overweight were significantly more likely to have dental caries (66.7 percent) when compared to those who were not overweight.

The recent public forums conducted by the Alaska Governor's Council on Disabilities and Special Education identified diet/nutrition as one of the several health care barriers with which this population needed assistance. Inappropriate eating practices, limited mobility, characteristics of certain syndromes, and alteration in body composition are contributors of obesity. The high level of obesity in this population makes them particularly at risk for high blood pressure, type 2 diabetes, coronary heart disease, stroke, gallbladder disease, osteoarthritis, sleep apnea, respiratory problems and some types of cancer. In addition to these risks, the negative social consequences of obesity contribute to the quality of life challenges for individuals with mental retardation.

The recent experiences of our members who participated in the Special Olympics World Games in Anchorage, Alaska indicate that the problem of obesity is not limited to the population in the United States, but is a problem around the globe. As our members completed heights and weights measurements on many of the athletes, we were asked by coaches not to discuss or even share the weight with the athlete. The concern here is the stigma associated with overweight as it impacts the individual's self-confidence and the chance that the individual may adopt a much less healthy eating behavior such as anorexia or bulimia. Clearly, there is a role for nutrition education in this population. Education on healthy eating behaviors, the importance of physical activity and in some situations medical nutrition therapy for individuals with more complicated diet-related diseases/conditions is required. Such services can be provided in a variety of settings, but should be a component of seamless health and social services offered to this population.

To meet the multiple needs of persons with mental retardation throughout the lifespan, the American Dietetic Association recommends the following measures:

—Provide nutrition services as an essential component of all services offered to the population with mental retardation.

—Maintain a strong national nutrition monitoring program to provide accurate, reliable, timely, and comparable data to assess status and progress and to be responsive to unmet data needs and emerging issues. The national data sources (i.e. National Health and Nutrition Examination Survey and the Continuing Survey of Food Intakes by Individuals) should seek to include a valid sample size among the population with mental retardation.

—Include a registered dietitian who has experience in the nutrition needs of persons with mental retardation in agencies developing policy in the areas of education, vocation, and health services at the federal and state levels.

—Collaborate with providers to endure that there are policies in place that promote family-centered, interdisciplinary, coordinated, community-based and culturally competent services.

—Encourage participation of qualified dietetics professionals on primary and specialty care teams and vocation, education, and residential programs that serves this population throughout the life cycle.

—Provide the opportunity for increasing the level of nutrition knowledge among all health care and service providers.

—Obtain reimbursement for Medical Nutrition Therapy, enteral/oral nutrition products, and feeding equipment as part of comprehensive health care for persons with mental retardation, regardless of diagnosis or living environment.

—Enhance opportunities for individuals with mental retardation to participate in nutrition assistance programs (i.e. Food Stamps, Congregate Meal Sites)

—Develop improved referral mechanisms between tertiary care centers and community-based providers programs.
—Develop and implement content and /or field experience that addresses the nutrition needs of persons with mental retardation in undergraduate and graduate nutrition programs and provide specialized interdisciplinary nutrition training for registered dietitian.
—Encourage a climate of health and wellness for persons with mental retardation throughout the lifespan.
—Promote nutrition research in an effort to continuously improve the quality of care provided to those with mental retardation.

Thank you for the opportunity to provide testimony on this important issue.

PREPARED STATEMENT OF PAUL BERMAN, GLOBAL CLINICAL DIRECTOR, SPECIAL OLYMPICS LIONS CLUBS INTERNATIONAL OPENING EYES

As the Founder and Global Clinical Director of Special Olympics Lions Clubs International Opening Eyes I was asked to testify before your committee in Alaska. However, due to time constraints, I was unable to do so. I thought I would share some of my experiences and ideas with you and your committee.

As Global Clinical Director of Special Olympics Lions Clubs International Opening Eyes for the past 10 years I have witnessed the development of our program. We have examined 10,830 athletes, donated 3,854 pairs of glasses and trained 1,078 eyecare providers. It has been a tremendous learning experience. We know that people with mental retardation receive inadequate vision and eye health care. Our research indicates that 66 percent of the athletes who we see have not had their eyes examined in three years. We know that 37 percent need new or different glasses and we even find that 18 percent of the athletes are wearing clinically incorrect glasses. We have also found that 18 percent experience eye health difficulty. Approximately one-third of these are serious.

Unfortunately many athletes get what we call "the quick and dirty". I am not sure that this is only the case for optometry and ophthalmology but also in other areas of healthcare. I, therefore, feel that the model that we have created which has been designed to provide care to the athletes has another equally important goal and that is the transformation of attitudes and the improvement of care. Our volunteer optometrists and other Healthy Athlete practitioners go back to their communities and become a resource for people with mental retardation where they are welcomed and treated with respect.

We know that people with mental retardation receive inadequate vision and eye health care. One of the things that we have learned, and actually Dr. Block and Dr. Siperstein (their study is prepared for publication) have proven, is that the attitudes of healthcare professionals are transformed when they volunteer for a Special Olympics Healthy Athletes event. This is critically important because the attitudes of healthcare professionals effect treatment.

If one doesn't think it matters, it doesn't matter. If one doesn't feel it is important to take time to ask that additional question to understand the person with mental retardation, one doesn't ask it. Because of poor attitudes and limited expectations of people with mental retardation many healthcare providers want them in and out quickly. One of the things that we know and I guarantee all of our volunteer optometrists is that after volunteering for a Special Olympics Healthy Athletes event they will never look at a person with mental retardation in the same way.

One of the topics that came out in the testimony was that it is very important for health care professionals to have an improved attitude toward people with mental retardation. As far as I know no one can do this better than Special Olympics. I, therefore, suggest that the Federal Government consider funding a program enabling Healthy Athletes to become part of the curriculum of Healthcare Professional schools. By experiencing the didactic portion on clinical techniques and communication skills and then volunteering to be part of Healthy Athletes the healthcare professional will not only improve clinical and communication skills but they will also experience an improved attitude. I believe if this was a standard part of the program between the 3rd and 4th year of the healthcare professionals education this could be invaluable and really achieve some of the goals of improving the quality of healthcare for people with, mental retardation.

Obviously additional work has to be done but quality is effected by attitude and attitude is something that can be improved by Special Olympics. One of the things that I guarantee all of our volunteers when I am giving my initial presentation is that they will never, ever look at a person with mental retardation in the same way after volunteering for one of our events. After training over 1,000 healthcare profes-

sionals throughout the United States, I have yet to have one of them say to me that this is not the case. I, therefore, think we have found a model that can be helpful in improving attitudes and encourage the government to support this program not only within the optometric field but also throughout all healthcare disciplines.

Naturally, if you need a more concrete proposal I would be glad to do so but I just wanted to share some of my thoughts with you and the committee. Wishing you and all those involved in improving healthcare to people with mental retardation much success.

ADDITIONAL COMMITTEE QUESTIONS

Senator STEVENS. Thank you very much. There will be some additional questions which will be submitted for your response in the record.

[The following questions were not asked at the hearing, but were submitted to the witnesses for response subsequent to the hearing:]

QUESTIONS SUBMITTED BY SENATOR TED STEVENS

QUESTIONS SUBMITTED TO JAMES ERVIN

Questions. The Lions Clubs International are to be commended for the tremendous philanthropic work that they perform internationally, and particularly for their support of the Special Olympics Opening Eyes Program. If a federal matching grant program could be created, would the Lions be interested in participating so that the vision care programs for persons with mental retardation could indeed be extended globally?

Answer. It was a great honor to have the opportunity to speak before your subcommittee on Monday, March 5, in Anchorage. And I'm delighted to provide ideas on how Lions Clubs International can expand its vision care programs in both the USA and internationally, to focus on the unmet needs of mentally retarded children and adults.

INTRODUCTION

We are very excited about the clinical model used at Lions-sponsored Opening Eyes events at Special Olympic games. It's a highly replicable model that can be incorporated into our existing vision care programs worldwide. Additionally, our Lions Clubs International Foundation (LCIF) has a long history of providing grants to institutes serving developmentally disabled children and adults, in both the developing world and the USA. This means we have the immediate opportunity to increase vision care services for this particularly at-risk population through our worldwide network of projects.

RECOMMENDATION

To expand eye care services for this population, we propose "Special Vision for Special People," a program that will combine Lions' existing sight services and our work with special needs organizations into one initiative. The key components would include:

Expansion of Opening Eyes Model.—Lions Clubs International presently supports the work of more than 250 institutes and programs worldwide that serve mentally and physically-challenged populations. These include sheltered workshops and vocational training centers in the USA, residential institutes for disabled children in developing countries, as well as various special education schools. The clinical model used at the Opening Eyes events, including the personnel already trained in that program, can be scaled up to provide vision care services at these institutes. Funding to train additional optometrists and eye care workers on the special techniques, and equipment, would be the only needed outlays.

Expand Opening Eyes Model to Lions camps for the disabled.—In nearly all 50 states and in more than a dozen countries, Lions operate summer camps for persons with mental and physical disabilities. More than 15,000 children attend these camps each year, and like the data uncovered on Special Olympic athletes, most are not receiving appropriate eye care services. These camps would provide a ready-made channel to reach more children in need if additional funding was available.

Expand vision care for families with special needs in the USA.—At present, virtually all our 14,000 Lions clubs in the USA are underwriting eye exams and eyeglasses for the needy and working poor. Since most private insurance programs and

even many state-assisted programs do not fund general eye care and eyeglasses, Lions clubs are often the only safety net for these people, many of whom are children. We can quickly expand the efforts of these 14,000 Lions clubs to subsidize eye exams and eyeglasses for children and adults who have a verified developmental disabilities and who do not qualify for other assistance. This can be done through a voucher-type program administered by LCIF without any need to increase or invest in new vision care services—it's simply a matter of these persons gaining access to existing services.

Expand Low Vision Services for the disabled.—LCIF recently stepped up its grantmaking in the area of low vision services and rehabilitation to deal with the increased incidence of vision impairment among children and seniors. Advances in life-expectancy have increased the number of people with permanent vision impairment stemming from diabetic retinopathy, glaucoma and macular degeneration—diseases which are among the major causes of disability in older adults. The need to expand low vision services for children is being driven by increased survival rates of premature infants, the vast majority of whom are plagued by vision disorders and other developmental delays.

We are presently funding state-wide expansion of low vision services in Illinois, Oregon, Washington State, West Virginia and are also funding similar projects in the Dominican Republic and India. We could double or triple our impact, and expand this effort to other states/countries, with the help of federal matching funds. We collaborate with the best agencies in the world for this work, including the Lighthouse for the Blind in New York and with Johns Hopkins University, where a major Lions Low Vision Clinical Center is located.

JUSTIFICATION FOR REQUEST—WHY WORK WITH LIONS CLUBS INTERNATIONAL?

Lions Clubs International presently runs the world's largest global blindness prevention program, called the SightFirst initiative, which focuses on eliminating the causes of avoidable blindness—presently, 4 out every 5 cases of blindness are unnecessary (World Health Organization, 1997). LCIF raised $146 million for this initiative from Lions between 1991–94, of which $105 million has been granted to 509 projects in 76 countries. Our technical partner is the World Health Organization and some key project partners include The International Agency for the Prevention of Blindness and The Carter Center. Thus far, the SightFirst program has strengthened eye care delivery systems throughout the developing world and the results have been noteworthy:

—2.5 million cataract surgeries have been performed on the needy
—9 million people suffering from river blindness are receiving the drug Mectizan annually, which is ⅓ the total of people being treated worldwide
—4 regional ophthalmic training centers have been developed at leading eye hospitals and public health institutes in Africa, South Asia and SE Asia. More than 2,900 eye care workers have been trained thus far
—82 eye hospitals have been built or expanded
—250+ eye centers have received technical assistance and upgraded training

Senator Stevens, we have the experience and the technical know-how to expand eye services to developmentally-disabled populations. We have been doing this since 1917, often without recognition and rarely with government funding. We sincerely hope that President Bush's emphasis on funding faith-based and community-based organizations, and "putting trust in local people," applies to civic groups such as Lions Clubs International.

We are the world's largest volunteer service club organization with 1.4 million members, including 453,000 in the USA. We have a track record of commitment to protecting the eyesight of those in need and have the capability of scaling up these programs with minimal overhead. The Lions Clubs International Foundation has administrative expenses that average only 9 percent over the last five years, a ratio which is among the best in the nonprofit industry. The majority of any federal matching funds would be directly invested in service delivery, not in administration. We would not only match federal funding dollar-for-dollar but would add extensive in-kind resources through our volunteer base.

NEXT STEPS

We would be pleased to present a formal proposal and would welcome any direction from your committee. We are also prepared to meet with your committee or staff members in Washington to discuss this opportunity in more detail. Thanks again for the opportunity to share our ideas and for your interest in the work of Lions Clubs International.

QUESTIONS SUBMITTED TO DR. TIMOTHY SHRIVER

Question. Special Olympics has unique experience in working with people with mental retardation relative to their participation in sports and to their receiving certain needed health care services. What could be accomplished toward meeting the health care needs of persons with mental retardation if an additional $3 million could be made available for programs and/or services to support this population? What could be achieved over five years if sustained additional resources could be brought to bear?

Answer. As I mentioned in my testimony, Special Olympics has been compelled to take a lead role in promoting the health of persons with mental retardation because others in the health and disability sectors have not made it a high priority. For more than three decades, Special Olympics has developed and implemented programs in sports training and competition for individuals with mental retardation. The health benefits of sports training and competition for those with mental retardation are widely acknowledged by family members and professionals in the fields of mental retardation, health and sports.

In recent years, Special Olympics has addressed the health needs of its athletes more directly through its Special Olympics Healthy Athletes Program and its Research and Evaluation Initiatives.

The objectives of the Special Olympics Healthy Athletes Program are threefold: To improve access and health care for Special Olympics athletes at event-based health screening clinics; to train health care professionals and medical students about the needs and care of people with mental retardation; and to collect and analyze data on the health conditions of people with mental retardation. Special Olympics Healthy Athletes provides health assessment, health education, disease prevention, and in many cases, corrective health care for Special Olympics athletes

So although we are a sports organization, we also believe that our role is to help define the health challenges of persons with mental retardation, to participate in the development of health promotion polices for them, to serve an advocacy role, to implement health screening and prevention programs that our athletes can readily access; and to make competent referrals to established sources who will willingly provide quality follow up care.

Specifically, if a single year appropriation of $3 million were made available, Special Olympics would undertake the following:

Expansion of the Special Olympics Special Smiles Program in all states, and down to the sub-state (regional) and metropolitan level. It costs $50 to screen each athlete for oral health. Accordingly, we could make oral health services available to approximately 60,000 additional athletes in dozens of additional locations.

Establishment of innovative community based models to enhance the delivery of definitive oral health services to Special Olympics athletes needing follow up care. In Egypt, our Healthy Athletes Program is delivered in part, by a specially outfitted van that travels to training and competition sites. We should pilot that delivery system in the United States.

Training of approximately 400 health professionals about the health needs of persons with mental retardation and special approaches for delivering quality care.

Creation of a web based provider registry of health professionals who are willing and qualified to provide health services to persons with mental retardation, so that persons with mental retardation, their families and advocates could identify accessible, appropriate sources of care.

Expansion of the Special Olympics Healthy Hearing ($110 per athlete screened) and Fun Fitness ($25 per athlete screened) programs beyond the pilot stage so that in the majority of states, such services would be available to Special Olympics athletes.

Development of a targeted, appropriate health promotion program for persons with mental retardation and stage one testing in six pilot states.

Targeted studies to better characterize the specific health care needs of sub-populations of persons with mental retardation, as well as studies to elucidate the barriers to persons with mental retardation receiving needed care.

If such funding could be sustained over a five-year period, with adjustments for maintaining newly expanded services, a full range of Special Olympics Healthy Athletes screening programs could be established in all states. Additionally, a cadre of thousands of health professionals would have been created through specialized training offered through Special Olympics. In short, the situation for tens of thousands of persons with mental retardation relative to accessing needed health care services would have been dramatically enhanced.

Question. How large a role would Special Olympics be prepared to play in such an undertaking?

Answer. Because of the importance of health issues to the functioning, dignity and quality of life for persons with mental retardation, and to their ability to have a healthy sports experience, Special Olympics would willingly commit to expending our Healthy Athletes programs with passion and a commitment to excellence. We believe that we bring unique knowledge, skills and perspectives to the service of persons with mental retardation at the grass roots level. In truth, we have not been able to identify a more likely source of leadership for these issues. With federal resources, we would improve the quality and length of life for people with mental retardation in a cost-effective, manner.

Question. Do you believe that there is a role for the public schools in addressing the health deficits of school-aged children with mental retardation?

Answer. I do believe that there is a role for the public schools in addressing the health deficits of school-aged children with mental retardation. First we need to identify the specific health needs for such students. Including a health assessment as part of an Individual Education Plan (IEP) would be a logical approach, since such plans already are mandated by law, schools are familiar with them, and health and the readiness and ability to learn are clearly linked. Because children with mental retardation who attend public schools may have extremely challenging home situations, linking students needing health care services to providers through school mediated mechanisms may be quite practical and cost effective.

Further, there are disturbing trends nationally regarding the health and fitness of school aged children. In fact, numerous health leaders, including the Surgeon General have declared overweight and obesity in American youth to be an epidemic that will produce dire health consequences for our population in the coming years. Moreover, there has been a continuing decline in participation in regular school based physical activity by students in all grades.

I would suggest that schools are an ideal setting for establishing Special Olympics sports programs that could produce sports opportunities for youth with and without mental retardation. Special Olympics Unified Sports® is an innovative community based approach that could benefit schools, students and the nation. I recommend that such an approach be considered in addition to the health screening and associated approaches I identified in my previous responses. Consistent with this, a separate funding stream would be appropriate. One might consider challenge grants to schools willing to partner with a local Special Olympics Program on a matching formula basis—i.e. the Special Olympics Program would receive a grant and the partner school would receive a grant. Both programs would offer in-kind and other available resources to the partnership.

QUESTIONS SUBMITTED TO DR. STEVE PERLMAN

IMMEDIATE ACTIONS

Question. What are the most important actions that could be taken immediately in order to have the greatest impact on the oral health of persons with mental retardation?

Answer. Dental care reimbursement rates for children with mental retardation should be indexed to rates that are market relevant. Several recent federal studies document that Medicaid dental rates in the states are so low that most dentists will not seriously consider participating. OBRA 1989 had provision for certain types of essential health services to be reimbursed at rates that can be demonstrated to produce desired outcomes—namely, receipt of certain types of services (did not include dental) by at-risk individuals.

Ultimately, rates that parallel local Usual and Customary (UCR) plus an incentive factor (say 5–10 percent) for additional time and costs that may be involved will be necessary to attract providers. This could be characterized as a case complexity adjustment factor, a time requirement adjustment factor, or simply a targeted incentive to address underutilization. The impact of rate enhancement could be tracked readily. Alternatively or additionally, Medicare, which includes virtually every health service other than dental, could add dental services for individuals with mental retardation at rates that are more market relevant than current Medicaid rates. States set Medicaid rates and have a long history of underpaying, resulting in few providers participating and only one-in-five eligible children receiving any dental services per year. The Medicare approach additionally could prevent people with mental retardation/disabilities from aging out of dental care, which is the unfortunate case with current state Medicaid programs.

Provide incentive funds for hospitals to establish special patient care programs.

Support targeted training programs in dental schools to properly train and indoctrinate students regarding the care of persons with metal retardation. Also, clinic support grants should be offered if the schools treat a certain volume of patients with mental retardation. If appropriate, given Special Olympics' unique experience, these grants could be funneled through Special Olympics, Inc.

A high level meeting with organized dentistry (ADA) or a targeted congressional hearing to secure their acknowledgement of the inadequacy of available care for persons with mental retardation and to gain their commitment to study the problem and develop specific solutions. Currently there is little evidence of their direct interest and investment in this issue.

For individuals who are being de-institutionalized into a group home or community residence, laws should mandate that an oral assessment and necessary follow-up care be arranged prior to the outplacement so that individuals do not drift out of a system of care already at risk.

DENTAL EDUCATION/DENTAL PROFESSIONALS

Question. What specifically needs to be done with dental professionals and dental schools to address your concerns?

Answer. Currently there are no requirements in predoctoral dental education for the care of patients with special needs. Studies in 1993 and 1999 demonstrated a woeful inadequacy in the number of hours of both didactic and clinical experience that dental schools offer to students. The same holds true for dental hygiene students. Efforts to secure a response to this issue have been futile, therefore establishing minimum requirements in predoctoral education for the care of patients with special needs for dental and hygiene schools as a component for accreditation is essential.

Establish dentistry as a mandated discipline for all federally funded University Affiliated Programs (UAP).

Expand accreditation requirements for the care of patients with special needs in General Practice Residency (GPR) and Advanced Education in General Dentistry (AEGD) programs to all specialties programs.

Provide incentive funds for dental schools to establish predoctoral programs for the care of patients with special needs.

Fund residency (post-doctoral training) programs for the care of patients with special needs (including stipends for fellows).

Offer student educational debt reduction in return for care of patients with special needs. This could be implemented through the states.

Given that pediatric dentists are the principal providers of dental care for most children and many adults with mental retardation, the two decade decline in graduate pediatric training slots for individuals intending to practice in the U.S. must be reversed. Targeted grants to dental schools will be required.

RESOURCES

Question. If additional resources could be directed toward resolving the oral health concerns raised before this Committee, how and where should they be directed?

Answer. We have to acknowledge that most practitioners have not been willing to treat patients with disabilities. As an example, in the past year, a survey was sent to all dentists in Massachusetts describing the crisis in access to care and whether they would be willing to treat people with disabilities. Over 5,000 requests were sent and several follow-up mailings were carried out. Only 249 positive responses were obtained. Out of these, only 61 would accept MassHealth (Medicaid). Therefore, we need to develop locations, facilities, and clinics committed to providing care for people with special needs.

Establish programs to develop and/or improve dental education programs for staff of community residential facilities (realizing staff turnover in group homes can be 80 percent per year).

State Boards of Dentistry should mandate that practitioners take some courses in special patient care as with other high priority continuing professional education areas (e.g. infection control, CPR, child abuse, etc.).

Fund projects that will:

1. Improve access to care, including transportation programs to get people to sources of care; and,

2. Provide information about the specific oral health problems that people with disabilities face.

That is what Special Olympics Special Smiles is trying to address. We are working on establishing and maintaining a data base of providers willing to treat people

with disabilities. Our screening program collects standardized data utilizing a Centers for Disease Control and Prevention Protocol. This will provide us with the knowledge of specific oral health problems of people with mental retardation. With this knowledge and additional resources, including improved reimbursement rates for providers, we can begin to seriously address the unmet need for dental care for persons with mental retardation.

QUESTIONS SUBMITTED TO DR. DAVID SATCHER

Question. I am pleased that you have decided to convene a Surgeon General's conference on the health status and needs of persons with mental retardation and to produce a conference report. What other programs and agencies should be lead participants in this undertaking and when do you anticipate this conference will take place?

Answer. We are developing the SG's workshop on the Issues of Persons with Mental Retardation. The conference will include input from a broad cross section of interested parties from federal, state and local organizations. In addition to representatives from DHHS, the Department of Education will be invited. Those concerned about the health needs of people with mental retardation including youth and family members, professional organizations and associations, advocacy groups, faith-based organizations, clinicians, educators, healthcare providers, and members of the scientific community will also be invited.

Question. Do we need specific national health objectives for persons with mental retardation for the Year 2010? How will you go about establishing such objectives?

Answer. At this time, Healthy People 2010 does not include specific measures for people with mental retardation. Baseline data is used to develop each objective in HP 2010. As baseline data become available for objectives on mental retardation, new measures could be considered for HP 2020. Developmental objectives can be initiated as a product of our workshop.

Question. What role can you play with the professional disciplines in order to get them to respond to the various issues that have been raised concerning the barriers that health care providers place in the way of persons with mental retardation being healthier?

Answer. There is a clear need to better train physicians to address the needs of children with mental retardation. The first step in educating health care professionals about the health care needs of people with mental retardation will be our upcoming workshop in which key professional organizations or disciplines will be represented. We anticipate the workshop will result in a Workshop Report or Call to Action, which will include specific recommendations to eliminate the barriers to health care services experienced by people with mental retardation.

Question. Healthy People 2010 calls for closing the gap in health literacy as a principal strategy for reducing health disparities. How can we create opportunities to increase the health literacy of people with mental retardation?

Answer. This will be one of the topics discussed at the Surgeon General's workshop. One of the goals of the Special Olympics is to increase health literacy among competing athletes through its healthy athletes program, which includes oral, hearing, and vision screenings and information on maintaining a healthy lifestyle. One of our workshop goals will be to find ways to build on the success the Special Olympics has already achieved and to develop better communication strategies for working with persons with mental retardation.

Question. The Children's Health Act established a National Center on Birth Defects and Developmental Disabilities at the CDC. In your opinion, is it adequately funded? If not, what funding level would you recommend based the needs identified in the report?

Answer. We would like to assist states and/or universities working with CDC to collect and report data on the prevalence of mental retardation at the state or regional level and to use this data as a foundation for collaborative studies into causes of and risk factors for mental retardation. When preventable causes are known, these states or universities should work with CDC to develop, test, and implement prevention strategies and evaluate the effectiveness of these strategies.

To that end, the President's budget request, which includes a $10 million programmatic increase for CDC's Birth Defects and Developmental Disabilities Account for fiscal year 2002, will permit CDC to begin to address these challenges.

Question. The report finds that the health care system provides financial disincentives for physicians and other care givers to work with patients with mental retardation. Do you agree? What can be done to rectify this situation?

Answer. This will be one of the topics discussed at the SG's workshop. We need to find ways to minimize the complexity of paper work required and adequately reimburse physicians for their services. We would like to get input from relevant stakeholders on this topic and to identify incentives for improving care.

Question. Special Olympics commissioned the Yale study because there is a woeful lack of data on the health status and needs of people with mental retardation. What can the U.S. Public Health Service do to remedy the lack of information on the health of this population?

Answer. A large barrier to addressing the specific health needs of people with mental retardation is the lack of available data. The Public Health Service, through the new Center on Birth Defects and Developmental Disabilities at CDC, has begun to work with a limited number of states to develop systems to monitor and track the health status of persons with mental retardation and other disabilities.

CONCLUSION OF HEARING

Senator STEVENS. Thank you all very much for being here, that concludes our hearing.

[Whereupon, at 11:55 a.m., Monday, March 5, the hearing was concluded and the subcommittee was recessed, to reconvene subject to the call of the Chair.]

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